EarlyBird Evaluation

Final Report

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EARLYBIRD EVALUATION

Final Report

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CONTENTS

Abstract

The EarlyBird programme is an early intervention programme for autism that was recently introduced in New Zealand. This report describes a series of studies that were carried out to evaluate this programme. A literature review identified theoretical foundations of the EarlyBird programme and principles that can be applied to the evaluation of such programmes. This formed the basis for an evaluation logic model. A new measure was specifically developed over the course of the evaluation to assess programme effectiveness, the Autism: Parent Questionnaire (APQ). A national study, using the APQ, monitored programme effectiveness for 53 families over the period of a year and found positive outcomes for families from their participation in the programme. An in-depth study looked at a sub-sample of eight families using the APQ along with other standardized measures. These families showed an improved outcome on the APQ, consistent with results from the national study. There was also support for the validity of the APQ in the cross-validation with other measures. Finally, an up-take study explored the extent to which this programme is accessible to the entire population of families who might need it. Several barriers to access to the programme were identified and discussed. Overall the evaluation found that EarlyBird is associated with beneficial results for participating families. Suggestions are made concerning the value of the programme in New Zealand, and how it might be further improved.

Executive Summary

This document presents the final report for the evaluation of the outcomes of the EarlyBird programme in New Zealand on behalf of the Ministry of Education.

The EarlyBird programme was developed and initially evaluated in the UK, where improved outcomes for parents and siblings were reported (Hardy, 1999). Part of the development and implementation plan for the EarlyBird programme in New Zealand was a commitment to ongoing evaluation of the outcomes of this programme, and specifically to establish whether any gains for participants are maintained over time. Initial data that was collected in NZ through the 2001 pilot study supported findings from the UK. In order to verify the pilot study findings and gain ongoing data and maintenance data an additional, larger scale evaluation was commissioned.

The aims of the current research were:

1. To develop a set of outcome criteria based on the theoretical literature around early intervention in autism, and the stated goals and objectives of the EarlyBird programme.
2. To evaluate the EarlyBird programme in light of these criteria and report on the maintenance of outcomes over time.
3. To establish how effective the questionnaire developed in the pilot study is in assessing programme outcomes, and produce a revised and validated tool for measuring the effectiveness of the EarlyBird programme.

An additional question that was subsequently raised on behalf of the Ministry of Health was:

4. To investigate to what extent the EarlyBird programme is visible and accessible to all those who would benefit from it.

This document describes how these aims were addressed by carrying out a literature review and four interlinked studies. A final overall discussion then synthesises the findings from all the studies.

In a review of the literature the principles that guide effective early intervention for families with autism were established. In many respects the EarlyBird programme is consistent with best principles, and utilises a range of therapies that have wide acceptance in the field, and in some cases, scientific support of their efficacy.

The development of an economical and valid parent self-report questionnaire was undertaken, suitable for use with early intervention programmes such as EarlyBird. This questionnaire was developed using samples of New Zealand parents, and was then used in the evaluation of EarlyBird reported here. The Autism: Parent Questionnaire (APQ) is a 25-item questionnaire, with established validity and sensitivity to changes over time from participation in the

EarlyBird programme. It is anticipated that the APQ will be useful in future evaluation studies of such programmes as a pre-post measure of programme effectiveness.

The evaluation of a national sample of EarlyBird programme participants supported the effectiveness of the programme. The APQ together with the CARS-P, was administered to 47 of the 53 families who attended EarlyBird throughout New Zealand during the period May 2003 to February 2004. The results show significant positive changes in APQ scores for the participating families. In addition there was a significant correlation between the APQ Stress subscale and the CARS-P b (stress component), providing support for the validity of the APQ stress sub-scale.

A sub-sample of eight families who attended the EarlyBird programme provided additional questionnaire data (Parent Stress Index, and Family Environment Scales) and videotaped observations. Results from this sample are largely presented in case study form. Although the observational data show few conclusive results, the APQ data, which included an additional data-point at baseline, provided additional evidence that strengthens the conclusion that observed positive changes were a result of participation in the EarlyBird programme. There was also additional support for the validity of the APQ family subscale.

Although the above studies provided support for the efficacy of EarlyBird, a further consideration was the access to the programme for the wider population of parents with autistic children. Families of autistic children who had not attended EarlyBird were identified and interviewed. Barriers to participation included perceived cultural appropriateness, difficulties with practical arrangements necessary to be able to attend as a couple (child-care and time off work), and long wait-times / limited provision in some areas.

In conclusion it is argued that the EarlyBird programme is beneficial for those families who participate in it. Specific recommendations to improve the delivery of EarlyBird in New Zealand include:

- making it more accessible for a wider population in New Zealand, especially those in geographically isolated populations, and those who may not be members of Autism New Zealand,
- making access to the programme easier either by facilitating child-care arrangements, or by offering alternative times (evenings or weekends perhaps),
- adapting it to the multicultural population of this country,
- reducing wait times,
- improving early identification to ensure that families can benefit from EarlyBird when their children are at the appropriate age.

General Introduction

This document presents the final report for the evaluation of the outcomes of the EarlyBird programme in New Zealand on behalf of the Ministry of Education. The evaluation was designed and implemented by Dr Angelika Anderson, Associate Professors Dennis Moore and Fred Seymour, and Christina Birkin from the University of Auckland in consultation with representatives from the Ministry of Education and Autism New Zealand.

Background

The Ministries of Education and Health jointly and in partnership with Autism New Zealand, were keen to develop a sound, theoretically-based, national, early intervention programme for parents of children with autism. As a result the National Autistic Society (NAS) EarlyBird parent education programme (from the United Kingdom) was piloted in New Zealand in 2001. This programme was implemented as part of an initiative by the government to contribute to a range of services for people with ASD and their families, including professional development and parent education initiatives. They also committed to ongoing research aimed at developing and documenting best practice and improving educational outcomes.

The EarlyBird programme was developed and initially evaluated in the UK, where improved outcomes for parents and siblings were reported (Hardy 1999). Initial data that was collected in New Zealand through the 2001 pilot study seemed to support findings from the UK. The purpose of this pilot included the development of recommendations for a larger New Zealand efficacy study of the programme, and the identification of methods for ongoing evaluation of the EarlyBird programme. Part of the development and implementation plan for the EarlyBird programme in New Zealand was a commitment to ongoing evaluation of the outcomes of this programme, and specifically to establish whether any gains for participants are maintained over time. In order to verify the pilot study findings and gain ongoing data and maintenance data an additional, larger scale evaluation was planned.

The aims of the current research, as specified in the Ministry of Education Request for Proposals were:

1. To develop a set of outcome criteria based on the theoretical literature around early intervention in autism, and the stated goals and objectives of the EarlyBird programme.
    a. To evaluate the EarlyBird programme in light of these criteria and report on the maintenance of outcomes over time.
    b. In terms of the processes involved in the delivery and up-take of the programme.
2. In terms of immediate, mid-term, and long-term direct (parent behaviours and attitudes) and indirect outcomes (child outcomes).

3. To establish how effective the questionnaire developed in the pilot study is in assessing programme outcomes, and produce a revised and validated tool for measuring the effectiveness of the EarlyBird programme.

An additional question that was subsequently raised on behalf of the Ministry of Health was

4. To investigate what extent the EarlyBird programme is visible and accessible to all those who would benefit from it.

The Current Report

This document reports the outcomes of a literature review and four interlinked studies, which were undertaken in order to answer the above research questions. The report is organised in six sections.

Section One: EarlyBird Project – Literature Review.
The principles that guide effective early intervention for families with autism are established by reviewing the current literature in this field, and the EarlyBird programme is then considered alongside these principles.

Section Two: General Method.
This section describes the general approach to the whole evaluation including the overall research questions, the underlying rationale and a logic model

Section Three: Questionnaire Development.
The development of a self-report questionnaire to be used with all New Zealand participants to measure changes in parental knowledge, skills and attitudes.

Section Four: National Study.
The results of administration of this questionnaire to 47 of the 53 families who attended EarlyBird throughout New Zealand during the period May 2003 to February 2004.

Section Five: In-Depth Study.
In this section findings are reported for a sub-sample of eight families who attended the EarlyBird programme. Additional questionnaire data (Parent Stress Index, and Family Environment Scales) and videotaped observations were used. These findings, which are largely presented in case study form, serve as a direct, low-inference measure of change in parental behaviour associated with the programme, and as data to triangulate the findings of the questionnaire.

Section Six: NAS EarlyBird Programme Uptake Study.
The degree of uptake of the EarlyBird programme by those eligible to participate, and on the barriers which may prevent families from taking part.

Section Seven: Overall Summary and Conclusions.
The findings of all four studies are discussed and summarised.

This report includes sections that have already been submitted to the Ministry of Education, or the Ministry of Health, and in some cases these reports have been released or published.

The literature review reported here is an up-dated version of the one already released, and currently featured on the MoE web-site. A version of this has also been published (C. Birkin, A. Anderson, D. W. Moore, & F. Seymour (2004). Evaluating the efficacy of parent-focused interventions for autism: how do we know what will work? Australian Journal of Early Childhood, 29(3), 42-47).

The questionnaire development section is essentially the APQ manual with the addition of further data. The up-take study is presented as reported to the MoH and is included here with permission. The purpose for including all these reports here was to be able to consider and discuss our findings within the framework of a broader picture.

We would also like to acknowledge at this point the assistance of two graduate students: Grace H. Kim, and Christina Tupuola. Their work was critical and very much appreciated.

SECTION 1

Introduction to Section One:

EarlyBird Project – Literature Review

This section is the latest and up-dated version of the literature review that we carried out as integral part of the evaluation, and which has been previously reported. It is included here again for the sake of completeness, and to orient new readers to the rationale behind the evaluation approach. The primary purpose of this section was to inform our evaluation, especially in terms of identifying

1. what theoretical foundations and rationales existed for the EarlyBird programme
2. a description of the EarlyBird programme, including previous evaluation work
3. measures and ways of measuring likely outcomes for the EarlyBird programme

This review informed the evaluation work that followed. It therefore concludes with a brief outline of the research plan.

Section One:

EarlyBird Project - Literature Review

Introduction

In New Zealand possibly as many as 1 in 150 people are affected by autism (Autism NZ Auckland Branch, 2002), with diagnosis of boys outnumbering girls 2:1 for classic autism and 6:1 for Asperger Syndrome (Ministry of Education, 2000). All children with autism represent a challenge to their families and to education providers, and are likely to need special resources and intervention throughout their lives. The functional deficits in autism can include acute sensory sensitivity, an inability to recognise patterns or salient features in the environment, and in some cases a lack of verbal communication. These difficulties may lead to high anxiety, insistence on routine, and stereotypic behaviours in children, and can impact on families and schools in the form of difficult behaviours such as tantrums, destructive and sometimes aggressive behaviours, and sensory shutdown. A number of events reported in the New Zealand media over the last ten years have highlighted the severe problems families living with autism spectrum disorder can face due to these challenges. The Ministries of Education and Health, jointly and in partnership with Autism NZ, have responded with a commitment to develop a sound, theoretically-based, national, intensive, early intervention programme for parents of children with autism.

As a result of this decision the National Autistic Society (NAS) EarlyBird parent education programme, an intervention first developed and implemented in the United Kingdom, has recently been piloted in New Zealand. The purpose of the pilot was to develop recommendations for a New Zealand efficacy study of the programme, including the identification of processes for evaluating the EarlyBird programme, and development of an outcome measure. Part of the development and implementation plan for EarlyBird in New Zealand is a commitment to ongoing evaluation of the outcomes of this programme, and specifically a desire to establish whether any gains for participants are maintained over time. Although the pilot study concluded that an exact duplication of the UK evaluation was not feasible due to the small number of families involved in the New Zealand pilot, the data that has so far been obtained in NZ suggests that findings could be comparable to those in the UK study. In 2002 the Ministry of Education contracted the authors of this review to conduct an evaluation of the EarlyBird programme in New Zealand. As part of fulfilling this contract we have reviewed the current autism literature. The aim of this review is to:

1. Outline the background to the EarlyBird programme and the current evidence for its effectiveness.
2. Inform the development of a set of outcome criteria which could be used to evaluate the programme, based on the theoretical literature around early intervention in autism and the aims of the EarlyBird programme.

Autism – Background and Etiology

Autism was identified in 1943 when Kanner (1943, cited in Kanner, 1973) categorised a group of children whom he described as displaying social aloofness, an indifference to others, and repetitive stereotyped play. Kanner did not identify a cause for this pattern of behaviours, but in one early theory (Bettelheim, 1967) it was attributed to the parenting deficits of a cold, unloving 'refrigerator mother'. This claim, the product of an era in which the trend was to minimise the role of biology in psychiatry, did not stand up to empirical investigation and was later discredited (e.g., Cantwell, Rutter, & Baker, 1978) to be replaced by biological theories.

Despite continued investigations over the intervening years, the exact aetiology of autism remains unknown. Current theory centres around evidence which suggests that a poly-genetically determined predisposition is subsequently overlaid with a variable and unknown combination of organic and environmental insults (Rutter, Bailey, Bolton, & Le Couteur, 1994). These insults potentially include, but are not limited to: prenatal or perinatal complications (Carr, 1999), elevation of blood serotonin, dopamine system impairments, viral infections, and immune dysfunction (Frith, 1989). It is thought that the diffuse neurological dysfunction which results from these combined mechanisms expresses itself in the cluster of deficits that Kanner labelled collectively as autism.

Wing (1971) described autism as a spectrum disorder in which degrees of impairment are represented. The spectrum ranges from Asperger Syndrome, in which there is fluent speech and a desire to interact with others despite severe problems in doing so, to classic autism. Wing identified three broad interacting zones of deficit (Wing, 1971): qualitative impairments in social interaction; qualitative impairments in communication; and restricted repetitive and stereotyped patterns of behaviour, interests, and activities. These three areas now form the basis of the Diagnostic and Statistical Manual (DSM- IV-TR) diagnostic criteria for autism (American Psychiatric Association, 2000, p.75), a degree of deficit in each area must be present for the diagnosis to be specified (see Appendix 1).

Early Intervention

In the wider field of childhood disorders and disabilities, early intervention programmes are designed to enhance the development of the preschool child with the aim of altering the developmental trajectory through increased opportunities for learning. The rationale of early intervention rests on knowledge about critical periods for learning and development in the early years, the early plasticity of the human brain with its corresponding opportunity for shaping capability and compensating for deficits through 'cognitive rewiring', and the benefits of establishing effective early patterns of learning and behaviour which will shape future development (Peterson, 1987). The importance and efficacy of early intervention for children at risk – whether this is due to environmental or biological factors – has been extensively researched and documented (e.g., Bronfenbrenner, 1974; Ramey & Ramey, 1998; Ramey, Yeates, & Short, 1984; Skeels & B., 1939; Solkoff, Yaffe, Weintraub, & Blase, 1969), and there is currently little dispute that early intervention can be successful in lessening the effects of a range of childhood disorders.

Outcome studies from the early intervention literature relating to developmental delay, and to autistic spectrum disorders, generally reflect this confidence, although some recent studies have queried early claims that intensive early intervention can result in normal functioning for children affected by autism. In an attempt to investigate Lovaas' (1987) findings which found nine out of nineteen children with autism gained normal functioning after two or more years of intensive early intervention, later research (Bibby, Eikeseth, Martin, Mudford, & Reeves, 2002; Mudford, Martin, Eikeseth, & Bibby, 2001) followed 75 children receiving parent-managed interventions of, on average, 30 hours per week. This more recent research failed to find significant gains on standardised tests for IQ, adaptive functioning or language after 12 months. Bibby (2002) notes the number of variables in operation within early intervention programmes, and the difficulty in determining those factors critical for efficacy.

Despite this, Rogers (1996) reviewed six efficacy studies relating to early intervention programmes for autism and concluded that intervention between the ages of two and four years resulted in significant developmental and learning gains. Rogers asserts that children in this age range make far more progress than older children receiving the same intervention. Green (1996) in a review of early intervention for autism added that interventions based on the principles of behavioural theory (commonly referred to as Applied Behaviour Analysis, or ABA) have resulted in substantial improvements in skills and reduction in problematic behaviours in children with autism, and that so far the best outcomes have been for children starting treatment between the ages of two and three. Green identified programme intensity, duration and integrity (compliance with empirically validated best practice standards for ABA programmes), and programme application across settings (e.g., preschool and home) as key components of the successful programme.

While there is conflicting evidence for the effectiveness of early intervention in autism, what does seem clear is that more information is needed about a) which elements of a given intervention are critical to ensure success, and b) what constitutes best practise in intervention (Rogers, 1996). Gresham, Beebe-Frankenberger, and MacMillan (1999) argue that questions of best practice regarding the age at which treatment is initiated, the intensity of treatment and treatment duration still remain largely unanswered. Recent research attention (e.g., Erba, 2000; Ramey & Ramey, 1998; Rogers, 1996; Smith, 1999) has been given to trying to establish the factors critical to early intervention, both in general, and more specifically in relation to interventions for autism.

Best practice in early intervention: elements of effective programmes –

In a review of outcome studies from the literature on early intervention with children who display developmental disabilities, or are at psychosocial or biological risk, Ramey (1998), described six factors which were repeatedly found to be associated with positive outcomes. These six principles of effective early intervention are:

1. ***Developmental timing:*** "Generally interventions which begin earlier in development and continue longer afford greater benefits to the participants than those that begin later and do not last as long." (p. 115).

2. ***Programme intensity:*** "Programmes that are more intensive (indexed by variables such as number of home visits per week, number of hours per day, days per week, weeks per year) produce larger positive effects than do less intensive programmes. Furthermore, children and parents who participate most actively and regularly are the ones who show the greatest developmental progress." (p. 115).

3. ***Direct provision of learning experiences:*** "Children receiving interventions that provide direct educational experiences show larger and more enduring benefits than do children in programmes that rely upon intermediary routes to change children's competencies (e.g., parent training only)." (p. 116).

4. ***Programme breadth and flexibility:*** "Interventions that provide more comprehensive services and use multiple routes [that is through both school and home, parents and teachers] to enhance children's development generally have larger effects than do interventions narrower in focus." (p. 116).

5. ***Recognition of individual differences:*** "Some children show greater benefits from participation in early interventions than do other children. Thus far these individual differences seem to be related to aspects of the children's initial risk condition." (p. 117).

6. ***Ecological dominion and environmental maintenance of behaviour:*** "Over time, the initial positive effects of early interventions will diminish to the extent that there are not adequate environmental supports to maintain children's positive attitudes and behaviour and to encourage continued learning related to school." (p. 117).

This information was reinforced by a recent report summarising best practice in relation to autism. Godfrey, Moore, and Fletcher-Flinn (2002) identified elements matching each of the above principles, and in addition highlighted the importance of using behavioural (ABA) techniques, and of involving the child's family. Bronfenbrenner (1974), writing about early intervention for developmental delays, suggested that the involvement of parents serves as a 'fixative' which may stabilise the effects of intervention by placing parents in a better position to reinforce learning and continue stimulating activities at home. This acknowledgement of the importance of family and parental involvement has led to the development of parent focused programmes in which parents of children with autism are assisted, through education, to understand and help their child.

Parent focused programmes

Research interest in parent focused programmes stems from an interest in determining the ways in which parent-child interactions influence children's development. Programmes focusing on parents can be conceptualised as drawing on one or more of the following theoretical rationales:

1. Parents are logical agents for change: Tharp and Wetzel (1969) propose parents as 'change agents' in a model where the therapist is conceptualised as 'consultant' and the child as the 'target'. The therapist is viewed as working through the

parent to bring about change in the way parents handle and treat their child, and thereby improve the child's behaviour. This model recognises that parent / child relationships are central to any change.

2. Parents are the experts on their child: Schopler (1984), in developing the TEACCH programme in the early 1970's, recognised parents as the most in-depth source of knowledge on their individual child. He advocated for the parent as the key decision maker with professionals acting in a support and technical advisory role.

3. Parent interventions are high intensity / low cost: Parent focused programmes have been seen as a way of developing a high intensity treatment at low cost. This theory focuses on the availability of parents as the people with most access to the child, and recognises the high cost of one-to-one programmes built on paid hours.

4. Parental programmes may aid stress reduction: The ability to manage and reduce behaviour problems may reduce parental stress. For example Bristol, Gallagher and Holt (1993)found that mothers who participated in programmes which helped them to understand, and to manage their child's learning and behaviour problems, showed decreases in symptoms of depression.

Parent focused programmes with autism have evolved to provide parents with effective ways of teaching their children and reducing the challenging behaviours associated with the pervasive needs in autism (Moes, 1995). Researchers have worked with parents of children with autism to successfully teach them to perform functional assessments of their child's disruptive behaviours, and plan appropriate interventions (Frea & Hepburn, 1999), to change child behaviours by using video feedback to alter their (parental) interactions with the child (Reamer, Brady, & Hawkins, 1998), and to reduce communication impairments through introducing play and language goals (Aldred, Pollard, & Adams, 2001). Since disruptive behaviours have been identified as a major source of stress for those who parent children with autism, programmes that teach parents to manage challenging behaviours have the potential to reduce parental stress, and maternal depression (Bristol et al., 1993).

Parent education programmes have proved to be cost-effective in providing immediate and short term gains in child functioning (e.g., Frea & Hepburn, 1999; Harris, Wolchik, & Weitz, 1981; Howlin, 1981). Information on long term gains from such parental programmes, however, reveals an inconsistent pattern of results regarding the generalisation and maintenance of the skills acquired by children (Moes, 1995). This highlights the need for ongoing support for parents to assist them to maintain new skills, and to deal with new challenges coinciding with their child's development. It also suggests the need for longitudinal research, which may add to our understanding of the long-term value of parent programmes, and the need to develop valid and reliable outcome measures which might be used in such evaluations. A number of outcome domains relevant to any family treatment programme were suggested by Carr (2000) in his comprehensive review of effective interventions for children and adolescents. These domains are:

1. Symptomatic improvement: Improvement in symptoms or target problems immediately following the programme or therapy.

2. Symptomatic improvement at follow-up: Improvement in symptoms or target problems more than three months after programme completion.
3. Systemic improvement: Improvement in aspects of the child's social network immediately following programme completion.
4. Systemic improvement at follow-up: Improvement in aspects of the child's social network at follow-up.
5. Positive clinical outcomes, as measured by some clearly defined criteria (e.g., the diagnostic criteria for autism).
6. Negative clinical outcomes: The percentage of individuals in the programme group that deteriorated from pre- to post-programme, and the drop-out rate.

Carr's criteria may provide a useful basis for the evaluation of parent-focused programmes for autism.

The previous section reviewed literature suggesting that parent focused early intervention programmes are potentially effective in meeting the needs of children with autism and their families. The conditions and criteria that characterise effective programmes have been outlined. In the following section the EarlyBird programme, its content, aims and objectives will be described, with a view to identifying the potential outcomes of this programme. Existing evidence concerning the EarlyBird programme is also reviewed. This includes discussion of the conceptual and theoretical foundations and empirical evidence regarding the efficacy of the EarlyBird programme and its components.

The EarlyBird Programme

The EarlyBird programme, designed by speech language pathologist Jane Shields, is a parent focused early intervention programme, which primarily provides families with information about the autism spectrum and how this affects their child (Shields, 2001). It is intended that parents attend the programme soon after their child has been diagnosed with autism, the programme is targeted at families with children with autism aged two to four years old.

The EarlyBird programme initially teaches about autism. Its premise is that a basic understanding of the condition is a necessary pre-requisite for parents to subsequently develop their child's communication and social interaction skills, or to manage difficult behaviour (Shields, 1999). Parents learn, firstly, to understand how their child experiences the world, and what underlies the child's behaviour; secondly, how best to build interactions and social communication with their child; and then finally how to analyse and pre-empt the development of inappropriate behaviours (Shields, 1999). Further, it is hoped that the programme will equip parents to make informed choices and decisions regarding their children, thus reducing reliance on experts and reducing parental stress. EarlyBird has been offered in many parts of the UK since its inception in 1997, and has also been adopted in Ireland, Malta, and Israel, and now in New Zealand.

EarlyBird is delivered via eight small group sessions during which parents are taught various skills. Between sessions parents make video recordings which are reviewed in the next session to allow them to monitor their use of these skills with their child. The targeted outcomes of the EarlyBird programme for parents are: increased understanding of autism; development of skills to support their child's communication and language; and the ability to manage difficult behaviours more effectively.

Evidence for the efficacy of EarlyBird programme and its components –

There have been two previous investigations into the outcomes of the EarlyBird programme, the first by Hardy (1999), and the second Macniven (2002).

The Hardy study involved 30 families; 18 participants in the EarlyBird programme and 12 non-participants. Data on the child was collected from two adults in each family. A quantitative approach was used to measure changes in:

a. adaptive (ability to cope with daily living skills) and cognitive functioning in the child;

b. child's communication level;

c. parent perceived severity of autism symptoms in the child;

d. stress in parents; and

e. joint parent / child interaction (engagement).

Measures of outcomes (a) - (d) were taken at two points prior to programme commencement (T1 at assessment, and T2 within the week before the programme), and two points post-programme (T3 at within 1 month of the end of course, and T4 three months after the end of the programme). The video recordings used to measure (e) were collected at T2 and T3. Families in the control group completed measures only at T1 and T2.

Significant differences were found in adaptive functioning as measured by the Vineland Adaptive Behavior Scale (Sparrow, Balla, & Cicchetti, 1984), with results showing a reduction in the gap between chronological age and developmental level pre and post programme. Significant differences were also found in parental stress, as measured by the Parental Stress Index (Abidin, 1995). In cognitive functioning, measured by the Receptive-Expressive Emergent Language Scale (REEL-2) (Bzoch & League, 1991), a communication assessment tool, no significant change was found in pre and short term post follow up although there was a significant increase between T3 and T4 follow-up. There was no change in severity of autism symptoms, as measured by the Childhood Autism Rating Scale (CARS) (Schopler, Reichler, & Renner, 1992), an autism screening tool.

In assessing parent-child interactions Hardy had originally intended to analyse video data using Bakeman and Adamson's "states of engagement", this being a measure of joint engagement in parent-child interactions (Bakeman & Adamson, 1984). However, due to the poor quality of recording on the tapes being used (these seem to have been the parent produced tapes recorded during the programme) the only measures were:

   a. Physical contact: total time during each ten-minute recording during which physical contact occurred between child and parent.

   b. Contact between the child and toys: total time during each ten minute recording during which contact occurred between the child and toy bag or toy.

   c. Word count: Parent conversation was transcribed and the total number of words used by the parent recorded.

Hardy reported no significant difference between T2 and T3 on the first two measures but in the same time period found a significant reduction in the number of words parents used in interactions with their child. There do not appear to be comparable data presented on any measures for the group of families who did not participate in the EarlyBird programme (control group).

In her conclusion Hardy (1999) notes that the evaluation did not control for the effects of additional interventions accessed by participating families which may have affected the results. She comments on the value of the videotape records as a measure of efficacy with the observation that recordings need to be of more reliable quality. Finally, Hardy notes that although questions were raised about assessment fatigue relating to the number of psychometric tools she presented to families in the study, this did not seem to be a significant problem for those families concerned.

Hardy's investigation provides some evidence for the efficacy of the EarlyBird programme in terms of reducing parental stress and improving adaptive functioning in children with autism. It is, however, unfortunate that her attempt to analyse observational data was hampered by poor quality recordings. A more rigorous analysis, possibly including information on number of ideas per sentence rather than simply a word count, may increase our ability to answer questions about the programme's effect on the behaviour of parents and children. Reporting from the control group at T3 and T4 would also add to our understanding of the effects of the programme itself as distinct from the effects of time and maturity on parents and children.

Macniven's (2002) study involved a larger number of participants, with 28 wait-list control group dyads and 21 experimental group dyads. Macniven analysed videotaped parent child interactions which had been taped by the EarlyBird trainer while dyads used a standard toy set. Videotapes were analysed using the AESOP: Autism and Interactive Engagement – A Coding System for Observing Play (a system adapted from the Play Observation Scheme and Emotion Rating (POSER) coding system) to measure changes during play sessions on a number of dimensions:

1. Parent Variables:
   a. Frequency of Parent Verbal Involvement
   b. Child Centred Speech
   c. Praise

    d. Verbal Control
    e. Behavioural Control

2. Child Variables
    a. Child Frequency of Vocalisation
    b. Clarity of Communication
    c. Responsiveness to Parent's Initiation
    d. Activity Level
    e. Intensity (involvement in play)
    f. Attentiveness / Absorption in Task
    g. Positive Affect
    h. Negative Affect
3. Joint Variables
    a. Reciprocity, Turn Taking and Mutual Responsiveness
    b. Conflict

Data was collected at three months prior to programme involvement and at pre programme for the control group, at pre and post programme for the experimental group, and at six month follow-up for both groups. Macniven found significant change for both groups (control or experimental) only on variables 1a,1b,1c,1d, 2b,and 3a. Since these differences occurred irrespective of which group the participating dyad was in the changes cannot be attributed to the effects of the EarlyBird programme and are likely to be the product of developmental change over time. The single dimension on which significant differences between groups was recorded was that of child frequency of vocalisation.

Vocalisation was defined as 'including any recognisable or unrecognisable speech, unintelligible grunts, squeaks or neologisms' (Macniven, 2002, p.132). While children in the experimental group increased their level of vocalisation, the vocalisation of those in the control group decreased, making this change very significant. However, Macniven's suggestion that increased vocalisation 'must represent increased attempts by the child to communicate with the parent' (Macniven, 2002, p. 82), seems to go somewhat beyond his evidence. He later links increased vocalisation to the significant differences in clarity of communication in children from both groups speculating that simultaneous increases on both of these two dimensions may result in better long term outcomes in terms of functional language for the children in the EarlyBird group. This is a claim which, as Macniven points out, would impact greatly on child behaviours should it be the case, and which warrants further investigation. Macniven also found significant negative correlations between the variable Parental Control and Child Clarity of Communication and the variables Child

Attentiveness and Reciprocity suggesting that a child centred approach by the parent may encourage more desirable child / parent interactions. This notion gains support if one considers Macniven's report that child vocalisations increased alongside Hardy's finding that parental language decreases during EarlyBird.

Both of these studies provide a tentative beginning to positive research data on EarlyBird outcomes, and invite further, more rigorous investigation of the programme.

Components of EarlyBird –

Elements of the EarlyBird programme content are derived from a number of pre-existing programmes. With the exception of the 'S.T.A.R Approach' these other programmes have been either specifically developed for use with families and children affected by autism, or, in the case of 'The Hanen Approach', have been subsequently adapted for use with this population. The following is a description of the programmes used within EarlyBird, including a review of the reported evidence to support the efficacy of these components.

Treatment and Education of Autistic and related Communication handicapped Children (TEACCH):

The North Carolina programme for the Treatment and Education of Autistic and related Communication handicapped CHildren was founded by Eric Schopler in 1966 at a time when Bettleheim's theory of pathological parenting (Bettelheim, 1967) was still widely accepted. TEACCH was pioneering in encouraging high parental involvement in teaching children with autism, and in accepting the parent as an expert on their child (Schopler & Mesibov, 1984). TEACCH currently takes the form of a state-wide community based programme (Gresham et al., 1999) which provides a range of educational options from full inclusion in the regular schooling system, to one-on-one individual programming. The extent and form of the education system used depends on the child's needs and abilities.

TEACCH provides education and training to the parents of children recently diagnosed with autism, encouraging these families to carry out a structured programme with their child (e.g., teaching tasks such as matching or sorting items by shape, colour, size etc., or imitating actions or sounds) in combination with regular contact with TEACCH professionals. The TEACCH philosophy emphasises the importance of reciprocal sharing of information between professional and parent, and maintains that involvement and a high level of interaction between home and other education settings is essential to a child's progress.

The principles which guide the TEACCH model are: (a) promoting adaptation both from the point of view of the child acquiring better skills, and from increased acceptance of autism and developing environmental adaptations to autism-related deficits ; (b) development of an individual education plan (IEP) using formal and informal evaluations; (c) prioritising behaviour therapy as an intervention strategy; (d) enhancing skills and accepting deficits in children and their parents; (e) use of visual structures and cues (such as picture schedules, and cue cards) to accommodate and overcome auditory processing deficits relative to visual processing strengths; (f) a holistic approach promoting multidisciplinary training for therapists and the use of consultants (Gresham et al., 1999).

TEACCH uses structured learning which capitalises on the relative strengths in visual processing found in autism. The four major components of teaching are physical organisation, schedules, work systems and task organisation (Schopler, Mesibov, & Hearsey, 1995). Consideration of the child's developmental and individual needs in terms of skills are considered within each of these components. The 'Iceberg' concept, which is referred to in the EarlyBird programme, comes from the analogy (Schopler, 1995) used within TEACCH to explain the concept of lawful behaviour, and to encourage an awareness and analysis of the reasons a child might act in a particular way. Schopler compares the presenting behaviour to the tip of an iceberg, the manifestation of a combination of underlying causes which can be analysed and understood in order to address the behaviour.

The TEACCH model is yet to be verified as an effective method for teaching children with autism. A study conducted in 1982 by Schopler showed a very large reduction in the instance of institutionalisation of individuals who had been involved in the TEACCH programme, compared to rates prior to the programme's inception. This study, however, was conducted during a period in which institutionalisation as a solution to caring for individuals with disability was being phased out anyway (Gresham et al., 1999). A second, quasi-experimental, study (Ozonoff & Cathcart, 1998) did not randomly assign subjects and failed to check the veracity of treatment implementation. It is therefore not possible to tell whether the gains in function made by the children in the experimental condition were due to the features of the TEACCH programme itself, or simply to extra time parents spent with their children working on skills at home. When considering the results of these studies it is important to note also that not all children involved in the TEACCH programme meet the diagnostic criteria for autism. Recent statistics cited by Lord and Schopler (1994) stated that about 65% of the children accepted for the TEACCH programme met the criteria for autism, with the majority of the remaining 35% meeting the criteria for pervasive developmental disorder, or for language disorders.

In a paper comparing the most visible and frequently cited educational treatments for autism Gresham et al. (1999) conclude that empirical evidence for the efficacy of TEACCH methods has not yet been established and that currently TEACCH does not enjoy the status of a well-established or probably efficacious treatment for autism. The EarlyBird programme draws from TEACCH the 'Iceberg' analogy and an underlying philosophy of parental involvement being key to any intervention.

SPELL:

SPELL was developed by the National Autistic Society (NAS) in the UK. It is not a programme as such, but rather an approach to designing learning environments, and a teaching framework to support learning in children and adults with autism (National Autistic Society, 2002). The acronym SPELL stands for **s**tructure, **p**ositive attitudes and realistic expectations of progress, **e**mpathy for the child, **l**ow arousal learning environment and **l**inks to other parties involved in child's care (Siddles, Mills, & Collins, 1997). These are the five elements of the education environment which the NAS suggest will facilitate learning in people with autism.

SPELL is currently used in a number of NAS run schools for children with autism (for example the Sybil Elgar, and Storm House Schools), and has been used to enable a trained observer to analyse existing educational settings and modify these settings as required. It is a system which, given what is known about autism, has very good face validity, but one on which there is currently no empirical research. The NAS do note that SPELL is continually monitored and assessed, and is still under development.

PECS:

The Picture Exchange Communication System was developed in the mid 1990's. It is a training system designed to teach children with autism self initiated functional communication, recognising the frequent deficits in verbal language in this population (Bondy & Frost, 1994). PECS teaches children to exchange picture cards for desired objects / activities, and takes advantage of the visual and concrete style of thinking which is a feature of autism. As a system it requires few pre-requisite skills, and those which are required (pointing to or handing over a card) are often already within the child's repertoire. PECS is designed to encourage the development of symbolic thought and the desire to communicate through creating the understanding that the environment can be impacted by communication. A lack of this understanding has been posited (Frith, 1989) as a primary barrier to communication in children with autism. It is hoped that once children can communicate using cards this may create the potential in some children to develop other forms of communication. PECS includes a structured teaching plan which parents can follow step by step, and uses behavioural teaching methods.

Schwartz et. al. (1998), in a study of PECS with preschool children with developmental disorders, found that on average these children were able to learn to use a picture to request an item within two months, and to build sentences (e.g., "I want ____") within four months. A long term study by the same authors demonstrated generalisation of communication skills to settings other than the one in which the skills were taught, and an increase in the use of other communication methods (such as gestures, vocalisations) to establish joint attention. Dooley, Wilczenski, and Torem (2001) reduced disruptive behaviours in a child for whom transition between activities was problematic by using a PECS based schedule board showing daily activities.

The STAR approach:

This approach to managing behavioural problems in people with severe learning disabilities is based on the behavioural psychology principle that all behaviour has some function. Therefore, by analysing the function of the behaviour taking note of the events just prior to, and following it, effective interventions can be planned. There is a well documented base of empirical evidence in the Applied Behavioural Analysis literature for the efficacy of interventions based on such functional analysis (e.g., Colman & Holmes, 1998; Ellis, 1999; Iwata, Dorsey, Slifer, Bauman, & Richman, 1982). The STAR model encourages functional analysis of four factors involved in the development and maintenance of problem behaviour: **s**ettings, **t**riggers, **a**ctions and **r**einforcers The approach describes how a therapeutic intervention package can be planned and executed using the following components:

1. Comprehensive assessment of the individual and behaviour of concern.
2. Modifying the setting in which the problematic behaviour occurs.
3. Modifying triggers that set off problem behaviour.
4. Replacing the problem behaviour by teaching appropriate alternative skills.
5. Encouraging the cessation of the inappropriate behaviour.
6. Encouraging self management.
7. Removing or altering the rewards of inappropriate behaviours such as attention, or desired outcomes (Zarkowska & Clements, 1994).

EarlyBird draws from STAR a model for analysis and modification of children’s behaviour.

The Hanen approach and OWL:

The Hanen Approach was designed by Ayala Manolson, a Canadian speech-language pathologist and is typically taught to parents by a speech therapist (Sussman, 1999). Hanen is a model of early intervention for children with delayed language which is based on involving and educating parents and early childhood educators in ways to improve the communication skills of these children. Its aims are described as educating parents through personalised and experiential learning approaches about ways to maximise their children’s communication using naturally occurring daily situations, and supporting parents through this process (Awcock & Habgood, 1998).

The Hanen approach encourages caregivers to integrate language learning into day to day routines, and to recognise opportunities for increasing language in everyday activities. Hanen emphasises knowledge of the developmental stages which children pass through in acquiring language, and explains strategies for encouraging and expanding language at each stage. The Hanen approach has been adapted specifically for use with children with autism (Sussman, 1999). When working with children with autism caregivers are encouraged to use short sentences, stress key words and accompany words with gestures or visuals to show children what is meant. This is likened to our natural response in communicating with someone who speaks a different language.

The Hanen process of encouraging language in children is summarised as: allowing the child to lead, adapting to share the moment by following this lead, and adding language and experience. Caregivers are also taught to use a strategy called 'OWL' which involves:

- **O**bserving the body language, expressions and focus of attention which allows us to recognise the child's feelings and needs
- **W**aiting and giving the child the time to communicate. It is emphasised that it is tempting to talk, or answer for children who are slow to respond.
- **L**istening attentively and encouraging children to express themselves when they do talk.

A handful of evaluations of the Hanen approach have been undertaken, and published in speech-language journals (Awcock & Habgood, 1998; Baxendale, Frankham, & Hesketh, 2001; Coulter & Gallagher, 2001; Dobson & Henderson, 1998). Unfortunately none of these studies relate either to children with autism, or to the Hanen approach to communication in autism. They may, however, give some indication of the success of the underlying philosophical approach of the technique, which is part of both programmes.

In all of the evaluations reviewed, qualitative data shows that the programme is reportedly enjoyed by, and helpful to, parents and childcare staff, with these participants reporting increases both in confidence and in their feelings of skill in supporting children's language development (Awcock & Habgood, 1998; Baxendale et al., 2001; Coulter & Gallagher, 2001). In one study parents were asked about changes in their behaviour with their child and, in contrast to parents involved in a traditional clinic type language intervention, those parents receiving Hanen training did report changes. It was not specified whether these changes were global or purely within the sphere of language interactions, but it seemed likely that any changes in the latter would generalise (Baxendale et al., 2001). In a study conducted in a pre-school setting staff reported that they noticed gains in social interaction (Coulter & Gallagher, 2001), a potentially important programme benefit if this holds true for children with autism. However, currently no study has reported evidence of increases in either receptive or expressive language of child participants as measured by standardised tests.

When viewed in light of current knowledge about autism each of these five programmes has considerable face validity in its approach to modifying the effects of the disorder. Although a search of the current psychological and educational literature shows little empirical evidence of efficacy for most of them, a shortage of empirical evidence does not necessarily mean that these interventions have no value, or are unable to create valuable changes in participants.

EarlyBird and 'best practice principles'

The literature reviewed above seeks to inform the evaluation of the EarlyBird programme in New Zealand by providing answers to the following questions: What is known about effective interventions for children with autism, what characterises effective parent focussed early intervention programmes, and what might be expected outcomes of the EarlyBird programme given its specified aims, the nature the programme, and its components? A further step in evaluating EarlyBird is to consider to what extent it accords with the general criteria outlined earlier in this paper for effective early intervention programmes and parent-focused programmes. In terms of criteria for effective interventions as outlined earlier in this paper:

- Developmental timing: The target audience for the programme is two to four year olds, which is within the age range during which early interventions are expected to be most effective.
- Programme intensity: Because EarlyBird is parent focused, and the direct programme goals are changes in parent behaviours, attitudes and knowledge, the intensity of the programme for any individual child will depend on the extent to which parents implement the new skills taught by EarlyBird.
- Direct provision of learning experiences: EarlyBird does not target children directly.
- Programme breadth and flexibility: EarlyBird has the potential to be very flexible and broad. Again, this depends on the extent to which parents apply the principles they learn to various domains of their child's life.
- Recognition of individual difference: EarlyBird has the potential to be highly individualised. Again, much depends on the parents.
- Ecological dominion and environmental maintenance of behaviour: EarlyBird has the potential for some environmental support for maintenance of effects since it encourages parents to continue to be actively involved in their groups. Again, the extent to which this occurs and promotes continued use of the principles taught will vary from group to group, and between parents within groups.

In terms of the criteria for effective parent focused interventions outlined earlier:

- EarlyBird expects that parents will be the agents for change in their child.
- EarlyBird encourages parents to become the experts on their child.
- EarlyBird therefore has the potential to be a high intensity–low cost intervention.
- EarlyBird is likely to be associated with a reduction in parent stress due to increased parental ability to understand and to manage their child's behaviour.

EarlyBird clearly targets a number of specific parent behaviours, which are directly related to key deficits common among children with autism (communication, social interaction, including play and joint attention, and behaviour). Provided that the programme succeeds in actually bringing about a behaviour change in parents, it should facilitate more adaptive development of the children. In implementing the EarlyBird goal to educate / inform parents EarlyBird participation should lead to increased knowledge, a better understanding of their child, and the ability to make better choices for the child. The specific programme goal to teach autism appropriate communication skills should encourage development of functional communication in children, and improved social relationships in the family. EarlyBird also aims to assist parents to develop routines which will support social interactions and the development of self-care skills. It encourages parents to teach their children to play, emphasising games that increase the likelihood of joint attention and child initiation. Finally EarlyBird aims to teach skills which will assist in the management of problem behaviours. This should lead to a reduction in these behaviour, and better management of the problem behaviours that do occur.

Outcome Measures for EarlyBird Evaluation

In order to evaluate the EarlyBird programme it will be necessary to assess the extent to which the programme brings about changes in parent knowledge, behaviour, and attitude / affect, as well as the effect that these changes have on the child, the family and the parents themselves. Potential indirect outcomes of the programme therefore include:

a. decreases in parental stress;

b. improvement in family functioning;

c. observable changes in parent and child behaviour;

Additional factors which could effect the effectiveness of the programme should also be monitored, including the following:

d. age of child at the start of the programme;

e. severity of autism;

f. information on other programmes accessed by the family;

g. the extent to which the programme is delivered as intended; and

h. the extent to which change in parent behaviour, attitudes and knowledge is maintained over time.

This review has undertaken an investigation of the literature surrounding early interventions in general, and more specifically the EarlyBird programme and its components. This literature leads us to believe that a sensible evaluation of the EarlyBird programme should include a number of elements. These elements, which are outlined in more detail above, include:

1. Information about the child and the child's family including severity of diagnosis and resources accessed prior to programme involvement.
2. Measurement of changes in the family environment, and in parental stress.
3. Measurement of behaviour changes in parents and children both in the short term and long term.
4. The level of parental satisfaction with the programme.
5. The degree to which the programme, as delivered in NZ, corresponds to EarlyBird as established and researched in the UK.

6. Information about those families who do not choose to participate in the EarlyBird programme and the reasons for this choice.

Conclusions

EarlyBird seems to be a soundly based programme which builds on best practice from a number of other approaches. Each of these underlying programmes uses methods which, given our current knowledge of the strengths and difficulties of the disorder, appear to be useful in working with children with autism. EarlyBird neither claims to be, nor is, a cure-all, rather it has a specific focus on early intervention, parent education, and parent support. These are, however, elements that should set off changes for the child if parents consistently adopt the new strategies promoted in the programme. EarlyBird should also assist parents in accessing and choosing appropriate specialist resources in the future as a result of their increased knowledge of autism and the range of options for intervention.

The current evidence for the effectiveness of EarlyBird is scant but positive. Further investigation is needed of both the immediate and long term effects of the programme. In line with Hardy's suggestions it will be useful to use a combination of psychometric measures and direct observation to collect information.

In addition, given that however effective a programme might be it is only of use in changing outcomes to the degree to which it is available to those who need it, and given that a government funded programme should, in principle be available to all who might benefit from it the investigation should also include consideration of barriers to participation. Information on who does, and who does not participate in the programme, and, of those who do, who benefits most, will help government and non-government (NGO) agencies to understand both the advantages and the limitations of EarlyBird, and will assist in the design of complimentary programmes in areas of need.

In line with these considerations and the findings of this review the remainder of the current document reports the findings of four interlinked studies which were used to evaluate the EarlyBird programme.

1. Development of a questionnaire to measure programme outcomes
2. A short longitudinal study, using this questionnaire, of all families participating in EarlyBird.
3. Eight in-depth case studies of participating families in which both psychometric and observational data was collected. This data was used to validate the questionnaire data.
4. An enquiry into awareness and uptake of EarlyBird by families who have children with autism.

SECTION 2

Introduction to Section Two:

General Method

This section describes the general approach to the whole evaluation, including the overall research questions, the underlying rationale, and a logic model. This is followed by a brief description of the 5 studies / components that together make up the evaluation. All studies, except for the up-take study were funded by the Ministry of Education. The up-take study was funded by the Ministry of Health, following an appeal by the research team. It was our view that such a study was required for a complete evaluation and both Ministries agreed this. The up-take study was however outside the scope of the original Ministry of Education contract and it was fortunate that the Ministry of Health was able to fund it. Because it was carried out within the general EarlyBird evaluation project, it is included in this final report, with permission, even though it has already been reported to the Ministry of Health, and released.

Section Two:

General Method

This section provides an overview of the general rationale and methodology used throughout the EarlyBird evaluation study. More detail on the methodology for each study is provided in the section relating to the individual study.

Research Questions and Aims

The aims of the research as specified in the Ministry of Education request for proposal were:

1. To develop a set of outcome criteria based on the theoretical literature around early intervention in autism, and the stated goals and objectives of the EarlyBird programme
2. To evaluate the EarlyBird programme in light of these criteria and report on the maintenance of outcomes over time.
    a. In terms of the processes involved in the delivery and up-take of the programme.
    b. In terms of immediate, mid-term, and long-term direct (parent behaviours and attitudes) and indirect outcomes (child outcomes).

Furthermore the RFP suggested that this work should build on work done previously, specifically by establishing how effective the questionnaire developed in the pilot study is in assessing programme outcomes, and recommendations for changes to this tool. This work included:

1. Determining the construct validity of this tool by comparing it to potential outcome variables identified by the literature and to the stated goals and objectives of the EarlyBird programme.
2. Editing and further developing this tool after its initial application with a sample of New Zealand parents with children with ASD and other participants in EarlyBird.
3. Reporting on how findings obtained using this revised tool compare with other, low-inference outcome measures.

Rationale and Development of the Logic Model

The rationale for the current evaluation was developed in response to the Ministry's aims for the project, taking into account recommended practice for the evaluation of treatment outcomes addressing the needs of children with autism, including early intervention initiatives.

The evaluation literature (see for example Green, 1996) suggested a number of elements that should be included in the evaluation of programmes for autism.

a. Describing the exact purpose of the treatment.
b. Describing exactly how the treatment is conducted.
c. Describing how treatment effects are measured.

d. Showing before and after data collected by independent, unbiased evaluators.

e. Showing follow-up data to ascertain whether programme effects are maintained over time.

The result of investigations into the best way to evaluate the programme was the production of a logic model. This model, shown in Figure 2.1 was used to guide the project throughout. The logic model illustrates the need to collect data about:

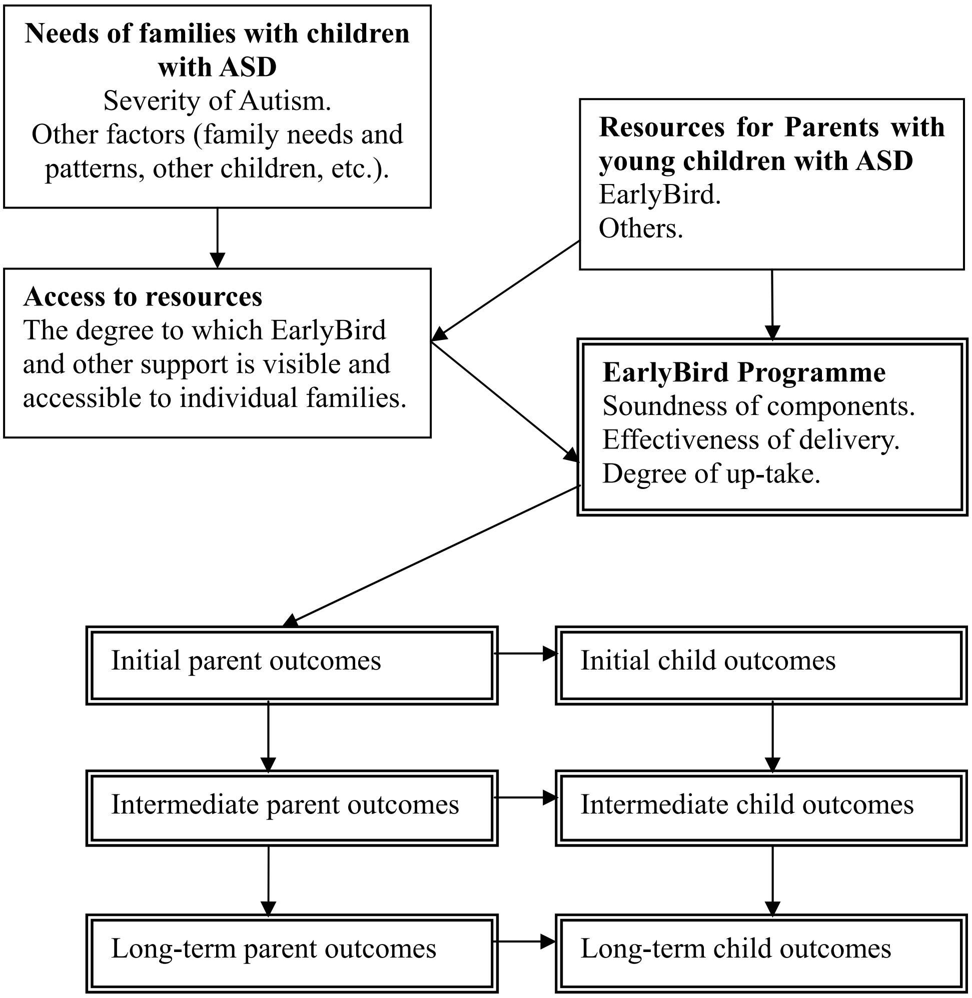
a. The factors affecting each participant family, including their access to resources other than the EarlyBird programme.

b. The EarlyBird programme itself, including the validity and veracity of its components as measured against autism early intervention literature (the literature review), and how consistently these components are delivered (treatment integrity).

c. How visible and widely available the programme is within the target population (uptake).

d. Parent and child outcomes due to the programme in both the short and longer term.

Figure 2.1: Logic Model



The Studies

The logic model suggested that several studies would be needed to effectively evaluate the programme. The research questions posed were answered using a short longitudinal group design (National Study), combined with a small number of in-depth case studies in which observational techniques were used in addition to questionnaires (In-Depth Study).

Part of the Ministry's goals for the evaluation was the production of a questionnaire, which could be used in an ongoing way as an evaluation tool for EarlyBird in New Zealand. This created a strong argument for using observational methods alongside the developing questionnaire to obtain low-inference data on the behaviour changes associated with the intervention (Maurice, Green & Luce, 1996). Therefore the inclusion of a low inference observational study which would run alongside the questionnaire assessment was planned, and became part of an in-depth study of eight families which included additional psychometric measures. This study served both to verify data from the questionnaire and to provide a direct, low-inference measure of change in parental behaviour associated with the programme.

To investigate whether changes reported as a result of the study were maintained over time the study was designed with data collection at pre-programme, post-programme and follow-up for the national questionnaire, and at four points in time (baseline, pre and post-programme and follow-up) for the in-depth study.

In addition the logic model had highlighted the importance of parents' access to the programme. However effective a programme such as EarlyBird may be, it is only able to affect outcomes in those families to whom it is available. A programme funded by the government should be available or accessible to all target families (in this case parents and families of preschool children with ASD). To this end a separate study was conducted to determine the rate of up-take of the programme by target families and to identify potential barriers. The uptake project was funded by the Ministry of Health. The studies are described in more detail below.

EarlyBird Project – Literature Review:

The principles that guide effective early intervention for families with autism were established by reviewing the current literature in this field, and the theoretical basis for the EarlyBird programme was considered alongside these principles. The review also identified the key components of early intervention programmes critical for successful outcomes. For instance Ramey and Ramey (1998) suggest that interventions which begin early and last an extended period of time, those which have a high number of hours of contact, provide direct, flexible, individualised learning experiences, and which recognise and control for the diminishing effects of early environmental support over time are most likely to be effective in the long term.

Questionnaire Development:

This study involved the development of a self report questionnaire (The Autism Parenting

Questionnaire) to be used with all New Zealand EarlyBird participants. The questionnaire was designed to measure changes in parental knowledge, skills and attitudes as a result of the programme. The seven dimensions measured (Knowledge about Autism, Communication, Play, Behaviour, Parental Stress, Confidence, and Family Functioning) were those identified in the EarlyBird programme manual and literature as being aims or goals of the programme, and also had credibility in the literature on autism early intervention as outcomes with social validity.

National Study:

This study provided a large scale evaluation of change in participating families resulting from participation in the EarlyBird programme. The aim of this study was to gather data from all families participating in the EarlyBird programme over the study period. The APQ questionnaire was administered to 47 of the 53 families who attended EarlyBird throughout New Zealand during the period May 2003 to February 2004. In addition, enrolment information collected by Autism New Zealand was accessed to provide demographic data.

In-Depth Study:

This study reports the findings of an in-depth investigation undertaken with eight families who attended the EarlyBird programme. Data was collected for this study at four points in time; 10 weeks prior to the programme starting (baseline), just before the programme start, immediately after the programme, and at 3 months follow-up. In addition to the information collected from them as part of the National Study these families filled in two psychometric measures (the Parental Stress Index, and the Family Environment Scale), and participated in 10 minute videotaped observations of play sessions at each of the four data collection times. The findings, which are presented in case study form, serve as a direct, low-inference measure of change in parental behaviour associated with the programme, and provide data which is used to triangulate the findings of the questionnaire and National Study.

NAS EarlyBird Programme Uptake Study:

This study was funded by the Ministry of Health, and reports on the degree of uptake of the EarlyBird programme by those eligible to participate, and on the barriers which may prevent families, particularly those from ethnic minority groups, from taking part. Participants (77 families) were interviewed by telephone about how accessible and acceptable the programme was to them. Face to face interviews with Maori, Pacific Island and Korean families provided data on the barriers specific to these groups.

These interlinked studies were carried out over a period of 14 months between January 2003 and March 2004. Ethical approval for all studies was obtained through the University of Auckland Ethics Committee prior to the commencement of the projects (Ethics approval numbers 2002/203 and 2003/076).

The use of a number of data collection methods and instruments was planned to allow for triangulation to verify the findings of the APQ. Use of instruments to provide at least two data sources is illustrated in Table 2.1.

Table 2.1: Showing dimensions of expected change and instruments used to measure them.

	Autism Parenting Questionnaire Dimensions							**Child**
	1 Knowledge	2 Communication	3 Play	4 Behaviour	5 Stress	6 Confidence	7 Family Functioning	
APQ	✓	✓	✓	✓	✓	✓	✓	
CARS P A								✓
CARS-P B					✓			
PSI					✓			
FES							✓	
Video	✓	✓	✓	✓				
Transcript		✓						
Interview				✓				✓

SECTION 3

Introduction to Section Three:

Questionnaire Development

This section reports on the questionnaire development in the form of an up-dated version of the previously reported manual that was developed and which is the final product of this work. Because what is presented here is actually a questionnaire manual, the language and the wording is not in a report style. For example, the instructions for administration are give in an imperative voice. Earlier reports have been submitted at various stages of the questionnaire development. This manual both describes the final questionnaire, and the whole process of its development. This version of the manual is an up-date of the manual previously submitted, now including data from the total sample, and the results of correlation analyses between subscales of the APQ and other questionnaires, which validate the subscales. Approval from the Auckland University Human Participants Ethics committee was granted for this section of the work.

Section Three:

Questionnaire Development

Introduction

The Autism: Parent Questionnaire (APQ), developed as part of the evaluation of the licensed use of the NAS EarlyBird programme in New Zealand, is a short, reliable self-report questionnaire designed to yield a measure of the relative effectiveness of parent-focused early intervention programmes such as the NAS EarlyBird programme (Shields, 1999; 2001). The normative data reported here also allow comparison with individuals' current parenting practices with their child with autism. The pre-post analysis provides an indication of parents' progress in a parent-focused intervention programme, and a measure of the programme's effectiveness.

Paradigm for Subscale Development

The parent book of the EarlyBird programme (Shields, 1999), and the literature on other intervention approaches for children with autism (e.g., (Anderson, Taras, & Cannon, 1996; Bitsika & Sharpley, 2000); Goldstein, 2002; Koegel, Symon, & Kern Koegel, 2002; Macalpine,1999; (McGee, Morrier, & Daly, 1999), suggest seven main components an early intervention programme for parents with children with autism could include: knowledge about autism, behaviour management, communication / language, confidence, stress management, family functioning and play. These components form the seven subscales of the present questionnaire. An explanation of the significance of each component is outlined below.

1. Knowledge about autism:
   The Knowledge subscale in the APQ contains items which assess parents' understanding of the ways in which children with autism are different from other children (items 1-4).

Knowledge about autism is essential in parenting a child with autism since many challenging child behaviours can be better understood in light of the underlying deficits (Shields, 1999). The TEACCH model (Schopler, Reichler, & Renner, 1992), for instance, uses an 'Iceberg' analogy to link the specific behaviour manifestation of the child with the underlying deficits and factors related to autism. Such an approach requires parental knowledge about autism, and about the way their child experiences the world, in order to understand and help them.

2. Communication:
   The Communication subscale has items which ask about the ways parents might increase their child's communication, such as matching language to the child's level, and using gestures and facial expressions to encourage turn-taking (items 5-8).

Communication involves getting a message across to another person and may be verbal or non-verbal. Although communicating with children with autism is challenging, there are strategies parents can use to develop communication with their child. The EarlyBird programme encourages parents to structure social routines with children to foster development of social communication. It teaches parents to simplify their language, and build on non-verbal communication. Use of prompts (physical, visual, and verbal) and interactions involving turn-taking are also encouraged. The Hanen approach, in a version adapted for children with autism (Sussman, 1999), encourages caregivers to use short sentences, and stress key words. Hanen also teaches caregivers to 'OWL' – that is **O**bserve body language and expression, **W**ait and give time for the child to communicate, and **L**isten attentively when the child does talk. In the Picture Exchange Communication System (PECS) (Bondy & Frost, 1994), children who lack functional communication are taught to exchange a picture of a desired object for the object itself.

3. Play:
   The Play subscale contains items about parent's use of play to interact with the child and to teach social interaction skills such as turn-taking and joint attention (items 9-11).

Children with autism display major deficits in social interaction, and in imaginative play (American Psychiatric Association, 2000). The quality of their play is often impoverished (Sherratt, 2002). Play is an important component of a child's development because it provides a means to develop social interaction and other skills. The EarlyBird programme attempts to teach parents to create opportunities for interacting and playing with their children.

4. Behaviour management:
   The Behaviour Management subscale assesses to what degree a parent is equipped with skills in managing their child's behaviour (items 12-15).

A major challenge for parents of children with autism is understanding and managing their children's behaviours. Often parents do not know why their child behaves in the way they do, nor how to manage their behaviours, especially when the child is non-verbal. The EarlyBird programme teaches parents to structure the setting, identify triggers, understand the function of behaviours, and control rewards. Functional analysis of behaviour (e.g., Iwata, Dorsey, Slifer, Bauman, & Richman, 1982) asserts that all behaviours serve a purpose and that analyzing the events prior to, and following the behaviour is crucial in designing effective interventions. Thus, parents should not only be able to identify the 'triggers' and consequences of their child's behaviour, but also know how to manipulate the setting and consequences to manage problem behaviours.

5. Confidence:
   The Confidence scale consists of statements about future perspective, optimism, and confidence in parenting (items 20-22).

Following a diagnosis of autism or Asperger's Syndrome, many parents experience feelings of inadequacy, which leaves them with low confidence. This feeling is likely to be due to lack of the specific parenting skills which would equip them to cope with the behaviour of a child with autism, or to a shortage of specialized services and interventions for children with autism (Koegel, Symon, & Koegel, 2002). Parent-focused early intervention programmes aim to develop parents' competence and confidence by educating and training them in understanding and parenting their child with autism. For example, in the EarlyBird programme parents work with other families who also have children with autism. Learning with and from others, by sharing stories and experiences may empower participating parents and reduces their feeling of isolation (Shields, 2001).

6. Stress:
   The Stress subscale assesses aspects of parental stress: perception of help available, degree to which autism dominates their life, and long-term responsibilities (items 16-19).

High levels of parental stress may be associated with factors outside the family, such as lack of help and support, as well as with factors relating to the child (Kasari & Sigman, 1997). Participating in family support schemes has been found to be associated with lower levels of parental stress (Bristol, 1984). Thus, parent-focused programmes that give access to parental support can be expected to reduce stress levels. It seems likely that there is a two-way relationship between stress and parenting ability; an increase in parenting ability reduces the level of stress, and vice versa.

7. Family functioning:
   The Family Functioning scale was developed to assess how well a given household is running, and to what degree the needs of all family members are met (items 23-25).

There is some evidence in the literature that the high levels of stress and exceptional demands associated with having a child with autism (e.g., Bouma & Schweitzer, 1990; Harris, 1994), as well as the effect this has on non-disabled siblings (Schubert, 1995; Sgandurra, 2001) can detrimentally affect family functioning. Although the EarlyBird programme does not directly target family functioning, family functioning may improve as a result of better parenting skills, reduced stress, improved functioning in the child with autism, and increased social support.

Scale Development

Test items in the APQ were developed in the following manner:

1. Seven dimensions (Knowledge About Autism, Behaviour Management, Play, Communication, Family Functioning, Confidence, and Stress) of early intervention training programmes for parents of children with autism were identified based on the literature, and in particular on the content of the EarlyBird programme. Each of these seven dimensions became a subscale in the questionnaire.

2. A second literature review was conducted to identify principles that could be used in designing questionnaire items, a rating scale and the questionnaire layout. The principles followed in the development of the questionnaire were:

   - *Items:* short and simple; avoid jargon, leading questions, and loaded words; avoid social desirability or response bias by including both negatively and positively scaled items (Oppenheim, 1992)
   - *Rating scale:* reliable and sensitive Likert scale; even number of points without a neutral point (Frary, 1996); consistent anchoring labels.
   - *Design:* questions of the same type should be grouped together; the questionnaire should require no more than 30 minutes to finish; instructions should be printed in boldface (Aiken, 1997).

3. A pool of questions designed to assess the seven dimensions were developed. A

total of 62 items were produced, with approximately the same number of items in each subscale.

4. The questionnaire was tested and refined through the two stages described below:

Stage 1: Administration and analysis of a pilot questionnaire:
A pilot study was conducted with the 62-item questionnaire with the aim of selecting the best 25 - 30 items. This pilot questionnaire was completed by 295 parents of children with autism of a wide age-range, who were recruited through Autism New Zealand (ANZ). This study produced a 27-item, Phase 1 questionnaire. Throughout this section this group of participants, who were involved in stage 1 of the questionnaire development, will be referred to as 'the normative sample'.

Stage 2: Administration and analysis of Phase 1 questionnaire:
The Phase 1 questionnaire was administered to 47 parents of pre-school aged children with autism, who were participants in the EarlyBird programme in New Zealand. The questionnaire was administered at three points in time; immediately before and after the programme, and again three months after completion of the programme, at follow up. The Phase 1 questionnaire was then further refined based on each item's sensitivity to pre-post change, and considering the number of items in each subscale. This refinement produced the Phase 2 questionnaire, which is the current form of the APQ.

Administration and Scoring

Parent questionnaire materials

The APQ materials consist of

1. the APQ Manual;
2. the scannable 25 item (2-page) APQ;
3. the APQ scoring sheet;
4. brief questions about the child with autism and the respondent's relationship to the child; and
5. instructions for administration.

These are provided in the Appendix. Instructions for completing the questionnaire including an example for marking responses are on the first page of the APQ.

Appropriate populations

The APQ was developed for use in early intervention programmes for parents of preschool children with autism. However, for pragmatic reasons, the normative data were collected from parents whose children had a mean age of 10.7 years (range 2 to 47, mode 5.0 years of age). This range of ages affected the normative scoring on the Play subscale in which there is a relationship between the age of the child and the subscale score since the older the child, the less likely the parent is to play with the child. A correlational analysis of the normative sample showed, however, no relationship between the age of the child and the **total score** on the APQ, indicating that variation in age is unlikely to significantly influence overall results. Therefore, with the exception of the Play subscale, the questionnaire can potentially be used as a general measure of parenting skills in parents of children with ASD regardless of the age of the child.

Professional requirements

The APQ can be administered and scored by individuals who do not have formal training in psychology or related fields. This means that coordinators and administrators of parent training programmes can use the APQ themselves for the purpose of ongoing monitoring of programme effectiveness. It is not recommended however that such personnel provide parents with individual feedback without advice from clinical professionals.

The respondents can complete the questionnaires without an administrator. However, respondents should carefully study the instructions and the information provided in the questionnaire before answering the questions.

Administration

Duration and administration setting: The APQ takes approximately 10 minutes to complete, but there is no time limit for completion. Respondents should be advised to set aside about 10 minutes to sit down in a quiet place, and to answer the items thoughtfully. The testing environment, which could be the respondent's home, should be well lit, and have a flat surface on which the respondent can write. The questionnaire can be answered using either a pen or a dark pencil.

Time of administrations: The pre-programme questionnaire (green) should be completed before participants begin the programme. Please hand out this questionnaire at the pre-programme visit, along with the participant information sheet (PIS), and either allow the parents to fill it in then, or ask that parents bring the completed questionnaire to the first session. Parents should keep the PIS for future reference.

The post-programme questionnaire (yellow) should be completed directly after completion of the programme. Please hand this out at the end of the last session, and either allow parents to fill it in then, or ask that they have it ready for you to collect at the post-programme visit.

The follow-up questionnaire (blue) should be completed six month after completion of the programme. Please take this one to the follow-up visit and ask parents to fill it in then.

At each point in time parents have the option of either handing the questionnaire to you or sending it directly to us in the freepost envelope supplied.

Instructions for administration: Ask the respondent to read through the instructions on the first page of the questionnaire. The following script is an example of instruction that could be given when administrating the APQ.

> *"The purpose of this questionnaire is to enable us to monitor on an ongoing basis the effectiveness of this programme. It is not a test of your performance*

> *as a parent. This questionnaire will take approximately 10 minutes to complete. Read the items carefully and rate how true the statements are for you on a 6-point scale, where '1' represents 'Not true at all' and '6' represents 'Definitely true'. Follow the example shown in the instructions and fill in the response bubble completely. Fill only one response bubble per item, and put an X over the response if it needs to be changed. There is no correct and incorrect answer. Remember to also answer the short questions on the last page of the questionnaire."*

Scoring

1. Score and sum the responses to each subscale shown in Table 3.1.

Table 3.1. APQ Scales, Items, and Scale Maximum and Minimum Scores.

Scale	**Items**	**Scale Min. – Max.**
Knowledge	1 – 4	4 – 24
Communication Skills	5 – 8	4 – 24
Play	9 – 11	4 – 24
Behaviour Management	12 – 15	3 – 18
Stress	16 – 19	3 – 18
Confidence	20 – 22	4 – 24
Family Functioning	23 – 25	3 – 18
Total Score	1 – 25	25 – 150

2. Write the sum of the scores for each subscale in the boxes provided on the scoring sheet.

3. The items on the Stress scale are scored in reverse, because they are negatively worded. This means that a low numerical value represents a high score and vice versa. Therefore the scores of these items need to be reversed. Do this by subtracting the sum of the responses on this scale from 28. For example, if the sum of responses on the Stress scale was 18, the reversed score is 10 (28 – 18 = 10). Write this score in the blank space labeled "**S ®**".

4. Sum the subscale scores to obtain the Total Score. Write this in the box labelled "Total Score".

Missing data

Subscale and total scores may still be calculated when the respondent has not responded to every item. However, the results and interpretation in such cases should be considered with caution. Scores should only be calculated if a) not more than one item is missing from a subscale, and b) not more than three items are missing from the entire APQ. When the above criteria are met, the steps to deal with the missing data are:

1. Identify the subscale from which the item is missing.
2. Calculate the average of the completed items in that subscale and round it to the nearest whole number.
3. Assign the rounded number to the missing item.

For example, if a respondent's item scores for Knowledge subscale are 4, 5, 5, and one item is missing, the average number is 4.7; that is, (4 + 5 + 5)/ 3 = 4.7. The missing item will therefore be assigned 5, the nearest whole number to 4.7, bringing the Knowledge subscale score to 19.

Note: These steps are adopted from the missing data convention used for the Parenting Stress Index (PSI; Abidin, 1995).

Normative comparisons and interpretation

The mean and standard deviations of the normative sample provide information that allows comparison of a respondent's score to the scores of a larger population. A description of the normative sample including its limitations is provided in Section Three.

A higher score on a subscale represents favorable parenting behaviours within the subscale domain, a lower score indicates fewer favorable parenting behaviours. The Total Score gives an overall indication of the respondents' parenting skills in relation to a child with autism.

Uses of the APQ

There are three ways in which the APQ scores can be used and interpreted:

1. *Assessing parenting behaviours:* The APQ can be used to assess the parenting behaviours of parents who have children with autism. The subscale scores and the total score for the questionnaire can be compared to standardized norms to provide information about the respondent's scores in relation to other parents of children with autism. This measure may be useful in indicating areas in which parenting support or training would be beneficial.
2. *Assessing progress in an intervention programme:* The APQ can be used in conjunction with a parent-focused intervention programme to assess a participant's progress in the programme by comparing the participant's scores pre- and post-programme, and, if desired, at short or long term follow-up.
3. *Evaluating an intervention programme:* The effectiveness of parent-focused intervention programmes can be evaluated by analyzing the change in parents' scores on the APQ. Significant, positive changes on given subscales in pre- and post-questionnaires suggest that the programme has an impact on the participants' parenting in these domains. It should be noted that the Confidence subscale needs to be interpreted with caution, since no significant change on this subscale was found in

the pilot study, which involved 47 participants in the New Zealand EarlyBird programme. The reliability, validity, and sensitivity of this subscale to change are still to be established in a larger study. In the meantime it should not be assumed that lack of change on the Confidence subscale reflects a deficit in the programme being evaluated. Confidence in the future may be impacted significantly by contextual factors, such as the availability of services. It is conceivable for example that as a result of increased information about what is best for one's child, confidence and future optimism might actually decrease, if such services are not available. This scale may therefore work quite differently in different contexts.

Normative Information and Psychometric Properties

Descriptive and normative information

The current norm sample consisted of 295 parents of children with autism recruited through Autism New Zealand (ANZ) in 2003. The sampling procedure was not random or stratified, and the parents were all members of ANZ. The age of their children ranged from 2 to 47 years old at the time of testing. The mean age was 10.7 with a standard deviation of 6.7, and the mode was 5 years of age. Twenty participants did not reveal their child's ethnic identity and among those who stated their ethnicity, 87% (*n* = 239) were European/ Pakeha, 7% (*n* = 20) were Maori, 3% (*n* = 7) were Pacific Islanders, and 3% (*n* = 8) were Asians (including Indian). Seventy nine percent (*n* = 233) of children were males and 21% (*n* = 54) were females. Table 3.2 presents the means and standard deviations of APQ scores for the normative sample.

Table 3.2. APQ Means and Standard Deviations for the Normative Sample

Scale	Scale Min. – Max.	N*	Mean	SD
Knowledge	4 – 24	288	18.3	3.6
Stress	4 – 24	285	11.2	4.5
Behaviour Management	4 – 24	275	17.8	3.7
Play	3 – 18	281	13.7	3.2
Family Functioning	3 – 18	287	13.3	3.0
Communication Skills	4 – 24	284	17.8	3.8
Confidence	3 – 18	284	13.4	3.2
Total Score	25 – 150	245	105.1	15.8

*N = 295. * the variability in N reflects incomplete response sets*

There are some limitations to the current normative sample and data, such as a wide variation in the age of the child and possible selection bias due to the way the participants were recruited. The next phase of the questionnaire development will provide normative data specific to pre-school children with autism.

Internal reliability

Alpha reliability coefficients (Cronbach, 1951) were calculated for each subscale, and for the total parenting score from the responses of the 295 parents recruited by Autism New Zealand (ANZ). These data are presented in Table 3.3. The coefficients for subscales ranged from .67 to .82 and the coefficient for the whole questionnaire (Total Score) was .87. These coefficients are satisfactory in indicating the internal consistency of the subscales and the questionnaire.

Table 3.3. Internal Consistency Reliability of APQ Subscales

Scale	**N**	**Number of items**	**Coefficient alpha**
Knowledge	288	4	.82
Stress	285	4	.77
Behaviour Management	275	4	.69
Play	281	3	.75
Family Functioning	287	3	.79
Communication Skills	284	4	.67
Confidence	284	3	.72
Total Score	245	25	.87

Factor Analytic studies

The sample of 295 parents recruited from ANZ served as participants in investigating the factorial validity of the APQ. The data were subjected to a principal axis factoring, and the seven components were rotated by a varimax rotation. The seven factors accounted for 64.6 % of the variance. The factor loadings are presented in Table 3.4. The pattern of factor loadings shows that each subscale is measuring a relatively distinct component of parenting children with autism.

Table 3.4. Varimax Rotated Factor Loadings for Items in each Subscale

		Factor						
Scale	**Item**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Knowledge	1	.646						
	2	.739						
	3	.777						
	4	.511						
Stress	16		.601					
	17		.662					
	18		.681					
	19		.684					
Behaviour Management	12			(.331)				.424
	13	(.364)						.485
	14							.555
	15							.660
Play	9					.787		
	10			(.305)		.595		
	11					.547		
Family Functioning	23				.665			
	24				.630			
	25				.717			
Communication Skills	5			.554				
	6			.693				
	7			.651				
	8			.359		(.334)		
Confidence	20						.521	
	21						.564	
	22						.806	

Note. N = 295. Loadings with absolute values less than .30 are omitted.

Table3.5. APQ Subscale Score Intercorrleations

Subscale	2	3	4	5	6	7
1 *Knowledge*	.320*	.411*	.279*	.359*	.335*	.272*
2 *Stress*	-	.138*	.195*	.518*	.133*	.371*
3 *Behaviour Management*		-	.418*	.313*	.387*	.308*
4 *Play*			-	.280*	.455*	.423*
5 *Family Functioning*				-	.206*	.401*
6 *Communication Skills*					-	.267*
7 *Confidence*						-

** Correlation is significant at the .05 level (2-tailed).*

The intercorrelations of the subscales are presented in Table 3.5. All subscales were significantly *(p* < .05) intercorrelated. The Spearman's rho coefficients ranged from .13 to .52, showing low to moderate intercorrelation of subscales. This means that a high score on the Knowledge scale for example is moderately associated with similarly high scores on all other scales.

Pre-Post analysis

The main purpose of the APQ is to assess change in parenting behaviours after participating in parent-focused early intervention programmes such as the EarlyBird programme. The responses from the 47 participants of EarlyBird programmes run in New Zealand between February 2003 and March 2004 were used to analyse the sensitivity of the APQ's subscales to pre- post change. Descriptive data for pre-programme, post-programme and three-month follow-up from participants in the EarlyBird programme are shown in Table 3.6 and Figure 3.1.

The result of an ANOVA on the data from pre-, post-, and follow-up questionnaires (N = 18) showed differences in the Total Score to be significant at the .05 level, as were the differences in scores on all subscales, except for the Confidence subscale. The results of Wilcoxon tests on the data from pre and post questionnaires (N = 25), and on the data from pre-, and follow-up questionnaires (N = 27) replicated this finding. In addition, there was no significant difference in response data taken from post-programme questionnaires, and follow-up questionnaires, except on the Family Functioning subscale (Z = - 2.6, p = 0.01). This suggests that parenting behaviours after the programme are stable over time (i.e., three months). Where there was a statistically significant difference, scores showed an increase from pre-programme questionnaires. This indicates that the EarlyBird programme has a positive effect on parents' behaviours and stress level. The number of participants (N) reported on in this section varies as a result of varying response rates and pre-, post- and follow-up times.

Table 3.6. APQ Range, Means, and Standard Deviations for the Normative Sample in Pre-, Post-Analysis

Scale (no. of items)		**N**	**Range**	**Mean**	**SD**
Knowledge	Pre	41	7 – 23	16.2	3.8
	Post	31	16 – 24	21.4	2.3
	Follow-up	30	18 – 24	21.3	1.9
Stress	Pre	41	9 – 18	13.1	2.9
	Post	32	8 – 19	15.0	2.9
	Follow-up	29	9 – 20	14.7	3.2
Behaviour Management	Pre	40	8 – 24	15.3	4.2
	Post	32	8 – 24	19.1	3.6
	Follow-up	29	10 – 23	19.2	3.2
Play	Pre	41	4 – 12	9.2	2.6
	Post	31	6 – 12	10.8	2.0
	Follow-up	30	6 – 12	10.9	1.5
Family Functioning	Pre	41	3 – 12	7.0	2.1
	Post	31	4 – 12	8.0	1.8
	Follow-up	30	7 – 12	9.2	1.5
Communication Skills	Pre	41	9 – 23	16.0	3.5
	Post	32	13 – 24	20.0	3.2
	Follow-up	30	15 – 24	20.0	2.8
Confidence	Pre	41	9 – 18	14.5	2.4
	Post	31	9 – 18	14.9	2.6
	Follow-up	30	9 – 18	14.4	2.2
Total Score	Pre	40	67 – 113	93.1	12.8
	Post	28	7 – 128	110.1	15.2
	Follow-up	28	84 – 127	109.1	10.3

Figure 3.1. Mean Scores of APQ Subscales in Pre-, Post-, and Follow-up Questionnaire

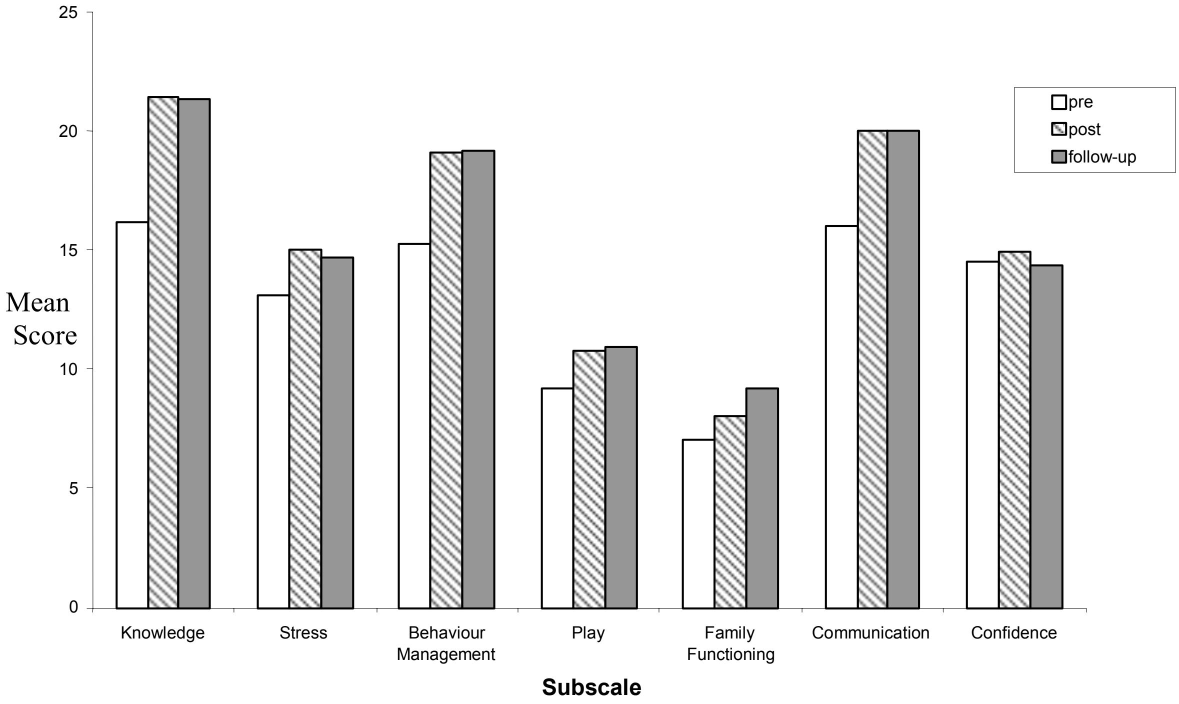


Figure 3.1 shows the mean scores on each of the subscales of the APQ at pre-, post and follow-up programme times. All subscales, except the Confidence scale, show significant improvement over time. While all subscales show sensitivity to change, significant change has not been found on the Confidence subscale. In fact, with some participants, there was a decrease in scores on the Confidence subscale after the programme. It should be noted that in comparison to other areas, the EarlyBird programme does not directly target parents' confidence. Furthermore, it seems possible that the new information and skills parents learn during the programme may take some time to integrate into daily living and that this is one reason that level of confidence does not show a significant increase. Confidence about the future may also depend to a large part on contextual factors such as environmental support and availability of resources. These factors may vary considerably between countries or even regions within countries. It is therefore possible that pre-post change in this scale is context-dependent.

Cross validation with other measures

In order to determine the construct validity of the APQ other established measures were administered alongside the APQ as part of the national and the in-depth studies reported in Sections 4 and 5. These measures were:

For the in-depth study: The CARS-P, The PSI (parenting Stress Index), and the FES (Family Environment Scales). (For a detailed description of the scales and the procedures see Sections

5 and 6 of this report.)

A correlation analysis between the APQ total, stress, and behaviour scales and the CARS-P-b (stress) at pre-programme for the national sample (n = 50) showed a significant correlation (Pearson Correlation =-.553 at the 0.01 level of significance) between the APQ stress subscale and the CARS-P b (stress). This result suggests that the APQ stress subscale and the CARS-P b (stress) measure related constructs.

Correlational analyses of the PSI, the CARS-P b, and the APQ stress scale for the in-depth sample (n = 8) show no significant correlations.

Correlational analyses of the FES Cohesion, Active Recreational Orientation, Organisation and Control subscales, and the APQ family subscale for the in-depth sample (n = 8) showed a significant correlation between the APQ family and the FES Control scale (at the 0.05 level of significance).

These results support the construct validity of the APQ stress and family sub-scales.

SECTION 4

Introduction to Section Four:

National Study

This section presents the national study. Presented are a brief introduction, the method, results, and a brief discussion of our findings with all the families that participated over the course of about a year. The separate literature review and overall method sections are in essence the more elaborate introduction to this section. The final discussion also elaborates more on the findings and integrates them with the findings from other sections of the report. Approval from the Auckland University Human Participants Ethics committee was granted for this section of the work.

Section Four:

National Study

Introduction

This section presents the national component of the overall evaluation. It is based on recommended practice for the evaluation of treatment outcomes addressing the needs of children with autism including early intervention initiatives.

The current section reports our findings using the APQ as well as one other established measure (the CARS-P) for the national sample of the EarlyBird programme in New Zealand for all programmes started between May 2003 and March 2004.

Method

Programme and participants

Data was collected from all EarlyBird groups that started between May 2003 and March 2004. Data was collected for each of these groups at three points in time:

1. Pre-programme (immediately before the beginning of a programme)
2. Post-programme (immediately after conclusion of a programme
3. Follow-up (three months after conclusion of a programme)

In all ten groups started the programme during this time: 4 received the full programme (2 in Auckland, 1 in Wellington, and 1 in Christchurch), and 6 the condensed programme (in Otago, Wanganui, Taranaki, Tauranga, Featherstone, and Gisbourne). Twelve different trainers were involved in the delivery of the programmes. This included the two senior trainers who were themselves trained in the UK. All other trainers were trained by Jane Shields in New Zealand. The total number of participating families was 54. The participants are described in more detail in the results section. The average age of the children at the start of the programme was 43.88 months (range 25 – 63 months).

Procedure

The first contact with the families was made by the EarlyBird trainers, at the pre-programme meeting, or the first session of the programme. Parents were informed about the purpose of the evaluation and invited to participate. They were given Participant Information Sheets and consent forms (see Appendix 2) along with the pre-programme questionnaires. After poor initial return rates the research team changed this procedure to have a member of the research team present at the first EarlyBird session to make the initial contact and invite parents to participate. Where possible the parents were encouraged to fill out the pre-programme questionnaire before the start of the first session. This was not always possible, and parents were supplied with freepost envelopes to send in their questionnaires by post. The post-programme questionnaires were distributed by the trainers, and the follow-up questionnaires were sent to each participating family by post. Each time freepost envelopes were included for the return of questionnaires.

Measures

The parents were asked to fill in the following questionnaires at each of the three data-collection points:

i. CARS-P a (symptom rating) and b (stress rating):

Child Autism Rating Scale-Parent Version (CARS-P; Bebko, Konstantareas, & Springer, 1987): *Child Autism Rating Scale-Parent Version* (CARS-P; Bebko, Konstantareas & Springer, 1987): This is a 14-item parental report rating scale directly adapted from the Child Autism Rating Scale (CARS; Schopler, Reichler, DeVellis & Daly, 1980) to gauge a parental perspective of their children's level of functioning. It consists of two parts:

- Part A measures the severity of symptoms over 14 areas, with each item referring to a characteristic, ability, or behaviour. Scores are rated on a 4-point scale ranging from 1 (normal for chronological age) to 4 (severely abnormal for chronological age).
- Part B assesses parental stress for each of these 14 domains on a 4-point scale from 1 (none at all) to 4 (extreme). The range for each Part is 14-56.

Although there is a substantial body of empirical evidence supporting the reliability and validity of the CARS, research into the psychometric properties of the CARS-P is scant (Morgan, Schopler and Sevin, cited in Tobing & Glenwick, 2002). This measure was chosen because of its use in previous studies, and its specific focus on child behaviour symptoms and parent stress in the APQ.

ii. APQ:

The APQ (Autism: Parenting Questionnaire) was developed specifically for this evaluation. The APQ consists of 25 items, scored on a six-point Likert scale ranging from 'not true at all' to 'definitely true'. It consists of seven dimensions or sub-scales containing various numbers of items (see Table 4.1 for a detailed description). As the APQ was developed during the course of this evaluation earlier groups of parents received a version of the APQ that contained more items. For this evaluation only the 25 items described were included in the analyses.

A high score on a given subscale represents favourable parenting behaviours within the subscale domain; a lower score indicates fewer favourable parenting behaviours. To achieve this, the negatively worded items on the Stress scale are scored in reverse. This means that a low numerical value represents a high score on this scale (i.e. high levels of stress) and vice versa. The Total Score gives an overall indication of the respondents' parenting skills in relation to a child with autism with a high score being positive.

Table 4.1: Description of APQ scales

Code	Scale	Description	Range
Know	Knowledge About Autism	assesses parents' understanding of how their children with autism are different from other children (items 1–4).	4–24
C	Communication	asks about the ways parents might increase their child's communication, such as matching language to the child's level, and using gestures and facial expressions to encourage turn-taking (items 5–8).	4–24
P	Play	contains items about parent's use of play to interact with the child and to teach social interaction skills such as turn-taking and joint attention (items 9–11).	3–18
B	Behaviour Management	assesses to what degree a parent is equipped with skills in managing their child's behaviour (items 12–15).	4–24
Con	Confidence	consists of statements about future perspective, optimism, and confidence in parenting (items 20–22).	3–18
SM	Stress Management	assesses aspects of parental stress: perception of help available, degree to which autism dominates their life, and long-term responsibilities (items 16–19).	4–24
FF	Family Functioning	assesses how well a given household is running, and to what degree the needs of all family members are met (items 23–25).	3–18
TS	Total Score		25–150

iii. Demographic and other information:

In addition to the questionnaires described above demographic and other relevant information on participating families was collected. This information was taken from the EarlyBird application forms from consenting families.

iv. Treatment integrity:

The National Autistic Society requires that New Zealand EarlyBird Trainers be monitored to ensure the NAS EarlyBird Programme is being delivered consistently and accurately. In response to this senior trainers in New Zealand developed a process of monitoring designed to be sensitive to the needs of the New Zealand trainers yet responsive to NAS requirements. This procedure is used as part of the regular training of EarlyBird trainers in New Zealand. It included some direct observations of new trainers during the first two courses they take, as well as the evaluation of other performance indicators (parents' feedback). The results of these observations for all the trainers involved in the evaluation were made available to the research team and constitute our measure of treatment integrity. A detailed description of the observation probes is in Appendix 3.

Table 4.2: Additional information and sources

Factor	**Source**
For the child with Autism:	
Date of birth	EarlyBird application form
Sex	EarlyBird application form
Ethnicity	EarlyBird application form
Diagnosis (Autism or Asperger)	EarlyBird application form
Severity of ASD	CARS-P
Language ability	EarlyBird application form
Behaviour difficulties	EarlyBird application form
For the Family:	
Description of family (SES, number of siblings, etc.)	EarlyBird application form
Resources accessed (SLT, respite care etc.)	EarlyBird application form
Additional programmes accessed	EarlyBird application form APQ coversheet

Data analyses

All data was entered into one SPSS file and statistical analyses were carried out as follows:

i. Analyses to cross-validate the APQ:

A major goal of the study was to develop a questionnaire that can be used in the future to continue to evaluate the EarlyBird programme and others like it. This work has been reported in Section 4 of this report. Further details on the questionnaire development and details of the cross validation analyses are also reported in that section.

ii. Analyses to identify programme effects:

Descriptive analyses of demographic information was completed as reported in the results section. Repeated measures. MANOVA were used to test for main effects of time, group and type of programme (full versus condensed) for total APQ and sub-scales, the CARS-P- a, and the CARS-P-b, as well as interaction effects of time by group or programme. The sample was then split into three age clusters (young, average, and old) using k-means cluster and age of child at the start of their programme. Repeated measures MANOVA were then carried out to test for main effect by age cluster, and interaction effects for age cluster by time for total APQ score and sub-scales, the CARS-P- a, and the CARS-P-b.

Results

i. Description of sample

A total of 54 families participated in the EarlyBird programme during the current evaluation study. Of these families, 47 consented to participate in our evaluation study, and 20 of these returned a complete data-set (pre-, post-, and follow-up questionnaires). Autism New Zealand EarlyBird application forms were accessed for all families who consented to participate. Table 4.3 presents details of the data collected from respective groups and shows the number of returned questionnaires at each point in time.

Table 4.3 Number of completed questionnaires per group

Course	Start date	Type	Number of participants	Number consented	Number of questionnaires returned		
					Pre-programme	Post programme	Follow-up
Wanganui (O)	6. 5.03	condensed	4	3	3	4	2
Taranaki (P)	26.5.03	condensed	6	6	3	5	4
Otago (Q)	6.6.03	condensed	5	4	4	2	4
Auckland (R)	27.7.03	full	5	4	5	3	3
Wellington (S)	28.7.03	full	7	5	5	5	4
Tauranga Hamilton (T)	17.9.03	condensed	6	5	4	4	5
Auckland (U)	24.7.03	full	7	7	7	5	7
Canterbury (V)	28.8.03	full	6	6	6	1	5
Featherstone (W)	4.9.03	condensed	4	4	4	4	2
Gisbourne (X)	26.2.04	condensed	3	3	3	3	3

Table 4.4 provides a demographic summary of the participants. The majority of the participants were NZ European, and the majority of the children had a diagnosis of Autism, and were male. Four of the children were described as having no receptive language with the majority described as having expressive language that is non-age appropriate.

Table 4.4: Summary Demographic Description of Total Sample showing the number and percentage of participants in each category

		Number of Participants	Percentage
Version of programme completed	Full	23	46
	Condensed	27	54
Ethnicity of child with autism	NZ European	24	48
	Maori	3	6
	Pacific Island	0	0
	Asian	1	2
	European	13	26
	Other	2	4
Gender of child with autism	Female	7	14
	Male	43	86
Diagnosis	Autism	45	90
	Asperger	1	2
Level of child's Receptive language (parent report)	none	4	8
	none – some	11	22
	some	19	38
	Some – good	7	14
	good	7	14
Level of child's Expressive language (parent report)	age appropriate	5	10
	not age appropriate	42	84
Does child have Tantrums	yes	38	76
	no	8	16

** numbers do not necessarily add up to 100 % because of incomplete data.*

ii. MANOVA results of Programme effects

Repeated measures MANOVA carried out for the APQ total and for the sub-scales of the APQ for the national sample showed significant changes over time as shown in Table 4.5. There were no significant between group effects for programme (condensed versus full programme) or by group. There were also no significant interaction effects (group or programme by time). Further analyses were therefore carried out for the group as a whole only. Two-tailed T-tests were carried out on the APQ total and sub-scales to identify points of significant differences. All APQ sun-scales showed some significant change at some point in time. Table 4.5 shows the degree of significance of differences between the scores of the APQ scales and each of the sub-scales over time (between pre-programme and post-programme; between pre-programme and follow-up; and between post-programme and follow-up). A - means no significant effect, * means a significant effect at the 0.05 level, and ** means a significant effect at the 0.01 level of significance. An equivalent analysis of the *CARS-P a* and *b* showed no significant effects at any point in time.

Table 4.5: Significance levels of effects over time for national sample, APQ and CARS-P sub-scales

Scale	Pre-post	Pre-Follow-up	Post-Follow-up
Total APQ	**	**	*
APQ know	**	**	-
APQ com	**	**	*
APQ play	-	*	-
APQ beh	**	**	-
APQ stress	-	*	**
APQ conf	-	-	**
APQ Family	-	*	-
CARS-P a	-	-	-
CARS-P b	-	-	-

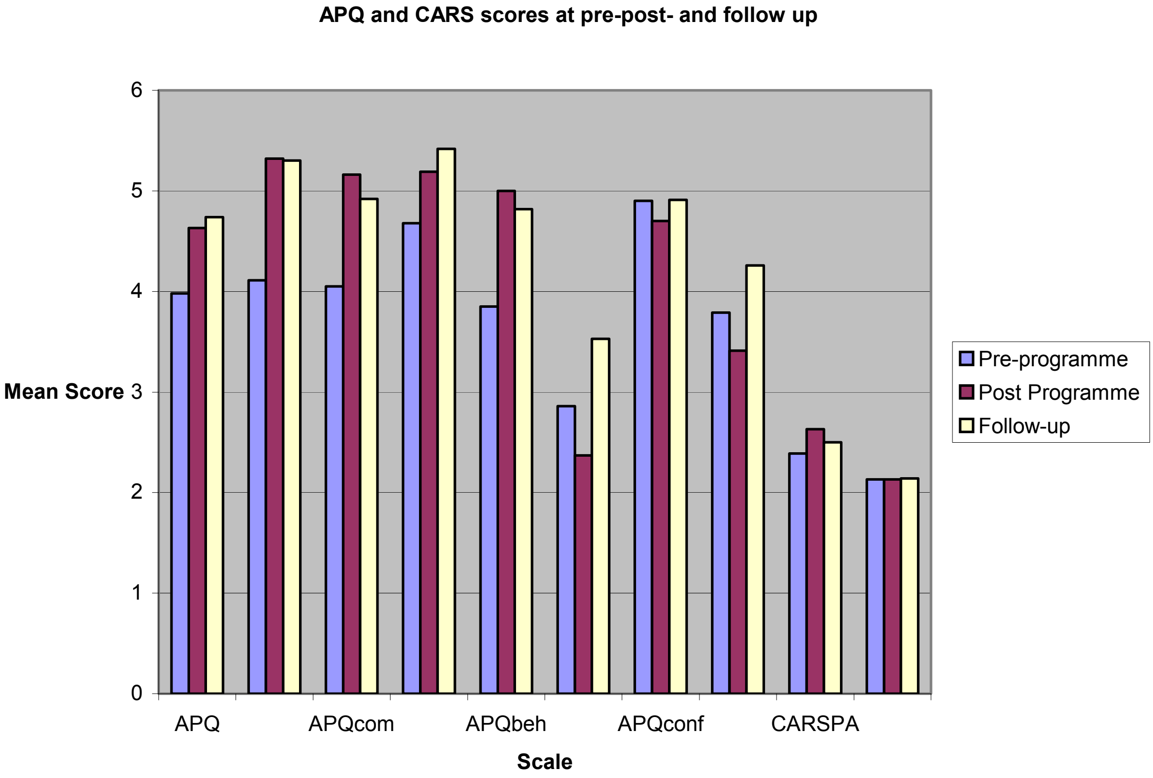
-	difference is not significant
*	difference is significant at p>0.05
**	difference is significant at p>0.01

Figure 4.1 shows the mean scores on the sub-scales and the total APQ and the mean scores on the CARS-P-a and –b at pre-post and follow-up times. The total APQ scores show statistically significant increases both between pre and post, and between post and follow-up times. The Knowledge, Communication, Play and Behaviour sub-scales show a significant increase between pre and post-programme. None of these subscales show a significant change between post and follow-up times.

The Stress, Confidence, and Family sub-scales show a different pattern of change. None of these scales show a significant change from pre – post programme. Scores on the stress subscale increase significantly between post programme and follow-up, showing a reduction in parental stress over this time period. The scores on the confidence scale increase significantly between post programme and follow-up times, and scores on the family scale increase significantly between pre programme and follow-up times.

There are no significant changes in CARS-P (a / b) scores.

Figure 4.1: APQ and CARS-P scores at pre – post – and follow-up times for the national sample



To test for any difference of programme effect by age of the child, the sample was clustered by the child's age (in months) at the start of the programme. Three clusters were formed: young, medium, and old. Table 4.6 presents the mean age (in months at the start of the programme), standard deviations, and number of children in each cluster.

Table 4.6: Description of age clusters

Age cluster	Mean age (months)	N	Std. Deviation
young	33.73	11	4.27
medium	43.81	26	2.65
old	54.18	11	4.64
Total	43.88	48	7.82

The age differences between the clusters were significant [F (2, 47) = 90.234 P< 0.001].

Repeated measures MANOVA carried out for the APQ and for its sub-scales for the national sample by age cluster showed that there were no significant between group effects, and also no significant interaction effects of group by time. An equivalent analysis of the CARS-P a and b also showed no significant effects.

iii. Treatment integrity

All of the trainers delivered the programme with adequate faithfulness to the manual. For the detailed report of the senior trainers on the performance of the trainers see Appendix 3.

Discussion

The data-pool that formed the basis of our findings originates from 47 families who participated in EarlyBird over the course of nearly a year. Though this seems like a reasonably large group of participants, few (20 families) returned a complete set of questionnaires at all points in time. This limits the extent to which it is possible to find statistically significant effects. This means that to be statistically significant differences need to be quite large.

The demographic composition of the total sample shows that some ethnic minority groups seem to be under-represented in this group of EarlyBird participants. There are a number of possible explanations for this. It could be that autism is not diagnosed as often or as early in those populations as it is for the rest of the population, or it could mean that members of some minority groups are less likely to participate on EarlyBird.

The results of the national study show significant increases in total APQ scores and the Knowledge, Behavior and Communication sub-scale scores between pre-and post-programme times, and also in total APQ score, Communication, Stress, and Confidence sub-scales between post-programme and follow-up times. Total APQ scores and all of the sub-scales except for the Confidence scale show a significant improvement between pre-programme and follow-up times. This suggests that over the time period of this study the responding parents improved significantly on all of the measures assessed by the APQ.

The results also suggest that some of the factors tapped by the APQ (Knowledge, Communication, Play and Behaviour) are more direct or immediate outcome measures, while others (Stress, Confidence and Family Functioning) may be indirect outcomes, since positive effects on these measures only appear after some time (at follow-up).

The observed improvement may be the result of participation in the programme, but alternative explanations cannot be ruled out entirely. An alternative explanation is that parents have acquired additional information, skills, knowledge and social support from sources other than the EarlyBird programme over the course of the evaluation. To eliminate this alternative explanation would have required an experimental design that included a control group. That was difficult given the constrains of the study in terms of time and resources, the relatively small sample pool, and the great within-group variability of children with Autism. The need to develop and validate a new outcome measure increased the press to aim for as large an experimental group as possible. A future study should include a control group. Instead of a control group we opted for a research design for the in-depth study that included an additional data-point at baseline, to allow a comparison in change over time with and without the programme, and may go some way to strengthening the evidence. These results will be reported in the next section of this report.

Further our results show that there are no significant differences between groups, or between the full and the condensed programme. This suggests that the programme is delivered with some consistency and that the condensed version does not significantly compromise treatment outcomes. There are also no significant between group differences by age of the child at the start of the programme. It needs to be remembered though that it is the parents who are the primary target of the EarlyBird programme, and the APQ outcome measure taps parent behaviours and attitudes, and is not designed to tap child outcomes.

Overall these results suggest that the EarlyBird programme as it is currently delivered in New Zealand is associated with increases in autism specific parenting skills and decreases in stress levels for participating parents regardless of type of programme or group.

SECTION 5

Introduction to Section Five:

In-Depth Study

This section presents the in-depth study. Presented are a brief introduction, the method, results, and a brief discussion of our findings with all the eight in-depth families, four from each of two groups that participated over the course of about a year. Again, the separate literature review and overall method sections are in essence the more elaborate introduction to this section. The final discussion also elaborates more on the findings and integrates them with the findings from other sections of the report. Approval from the Auckland University Human Participants Ethics committee was granted for this section of the work.

Section Five:

In-Depth Study

Introduction

The in-depth study had two related primary aims. The first was to find out whether there was a change over time due to participation in the EarlyBird programme as indicated in a range of psychometric and observational measures in addition to the APQ. The national study found an improved outcome for those families who participated in the EarlyBird programme, on the APQ, but not on CARS-P scores. More extensive multi-method evaluation was not possible with families participating in the national evaluation due to the large number involved. The second aim was to provide further validation of the APQ, through comparing change scores on the APQ with other psychometric measures and behavioural observation of a parent-child interaction, and through intercorrelations between established questionnaire measures for family functioning and stress and related sub-scales of the APQ.

Thus, the first hypothesis was that the eight parents involved in the evaluation would change on the APQ and on other measures as described in the method section; and that the APQ would correlate with other measures.

Method

Participants

The eight families who took part in this study were all EarlyBird participants who were also included in the national study. Each child had a diagnosis of either autism or Asperger's Syndrome, and was aged between two and five years old. Four of the families lived in the Tauranga/Hamilton region and four in Auckland.

Measures

All participants of the in-depth study were also participants of the national study, and received the same questionnaires as the national sample did: The *Autism: Parent Questionnaire* (APQ) and the *Child Autism Rating Scale-Parent Version* (CARS-P; Bebko, Konstantareas & Springer, 1987) as described in Section 5 of this report.

In addition these families were also asked to fill in the following questionnaires:

Family Environment Scale (FES; Moos & Moos, 1994):

This is a 90-item inventory completed by parents that assesses three family dimensions; relationships, personal growth and system maintenance, through 10 subscales. This measure was chosen because it specifically targets family functioning, a target of the EarlyBird programme and a subscale of the APQ. Items are presented in a True/False format, with scores for each subscale ranging from 0-9. There are three forms of the questionnaire; R (real), I (ideal), and E (expectations), with Form R being used for the current study. Its purpose is to gauge individuals' perceptions of their family's current functioning. A high score on each of the subscales indicates that the family is high on that measure. Only four of the ten subscale scores were included in this study as they were thought to provide information most relevant to the purposes of this study. These subscales are as follows:

1. *Cohesion (C):* The extent to which family members are concerned, committed and provide support for each other.
2. *Active-Recreational Orientation (ARO)*: The extent to which the family actively participates in social and recreational activities.
3. *Organization (ORG)*: The degree of importance a family places on planning and structuring family activities and responsibilities.
4. *Control (CON):* The extent to which the family uses set rules and procedures to run family life.

The Cohesion subscale has been found to have good internal consistency over a two-month period with an alpha of .78, while its' two month test-retest reliability has been found to be .86. The internal consistency for the ARO subscale is adequate at .67, as is its two month test-reliability at .77. Both the internal consistency and the two-month test-retest reliability of the 'Organizational' subscale were found to be good at .76, while the internal consistency and two-month test-retest reliability for the 'Control' were .67 and .77 respectively (Moos & Moos, 1994).

Parental Stress Index (PSI; Abidin, 1983):

This was developed to help identify stressed parent-child systems and facilitate intervention before the development of behavioural and emotional problems. The short form (PSI/SF) was utilised in this study as an additional measure of parent stress. It is made up of 36 items that map onto three subscales; Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC). Each subscale consists of 12 items and the combined scores of the three subscales contribute to the Total Stress score. A high score on each scale indicates a high level of stress. The PSI/SF is scored on a five-point Likert scale ranging from 'strongly agree' to 'strongly disagree'. The range of possible scores for each subscale is 12-60, while the range of possible scores for the total stress score is 36-180. Parents who obtain a Total Stress score of 90 or above (90th percentile or above) are considered to be experiencing clinically significant levels of stress.

The test-retest reliability and internal reliability of the three PSI subscales were as follows; PD- .85 and .87; P-CDI- .68 and .80; and DC- .78 and .85. The Total Stress test-retest was found to be .78 and .85.

Behavioural observations from video film:

Several factors were considered in designing the observational evaluation. These included focusing directly on parental behaviours targeted by the EarlyBird programme and related child behaviours; collecting data in the setting where the child would usually play, and carrying out observations in a similar way to that used in the EarlyBird programme. Each video recording session captured between 10-12 minutes of parents playing with their child, with a standard set of toys. Only six minutes of these segments was used for the observational analysis, starting from immediately after the two minute point up to just before the beginning of the eighth minute. Thus, only a sample of behaviour was targeted, so as not to impose further than necessary on families, and in accord with the wishes of the EarlyBird programme managers.

Child behaviours were scored for on-task, off-task, or unscorable (as described below), using a 10 second time sampling method. In each 10 second interval, the behaviours that occurred longest was scored. For example, if 'on-task' behaviour occurred for 4 seconds, off-task' behaviour for 3 seconds and unscorable behaviour for 3 seconds, then the interval was scored as being 'on-task'. Data collected in this way was reported as the percentage of intervals in which the target behaviour occurred.

The following behaviours were coded:

1. *Child on task behaviour:* This was defined as child is engaged in either playing alone or in interactive play. *Play* is when the child is engaged in the manipulation of toys and equipment in ways they were intended to be used. It also includes imaginative and symbolic use of equipment. For example, pretending blocks are cars.

2. *Child off-task behaviour:* This was defined as the child not engaged in 'On task' behaviour.

3. *Unscorable:* This was defined as child is off camera and/or playing with video equipment.

Other child behaviours were coded on an event basis; in particular if a child initiated an interaction, or if they displayed aversive behaviours during any 10 second interval, this was scored. Such an event was scored only one time per observed 10-second interval.

Data collected was reported as the percentage of 10-second intervals in which a particular behaviour occurred.

4. *Child initiated interaction (I):* This event was defined as making a deliberate and definite attempts to involve parent in new activity, with a different toy. For example, mother and child are busy playing with bricks. The child turns around, gets cars out of the bag, begins to play with it, and tries to engage the parent in the new game.

5. *Child aversive behaviour (A):* This behaviour category included general disruptive behaviour such as crying, whining, and yelling. It also included negative physical behaviour such as attempted or actual bodily attack and attempted or actual damage to objects.

Adult behaviours were also coded and scored on event occurrence basis, in the same way as the child events.

6. *Turn taking:* This was defined as the parent deliberately using strategies to initiate turn taking. Turn taking is defined as an action that is performed repeatedly by first one, and then the other play partner in a reciprocal manner with each waiting for the other to finish before starting their turn.

7. *Following the child's lead:* This was defined as occurring when the child has sustained attention to a target object/activity or intentionally communicates about an object or activity, and parent responds by following and building on that object/activity.

Observer agreement was assessed on 20% of the data for each family, and included data for each point in time. Percent agreement was calculated on an interval by interval basis as the number of agreements multiplied by 100, over the sum of agreements and disagreements. The inter-observer agreement of "on task" behaviour was 92.07%, child behaviours 96.99% and parent behaviours 97.21%.

Verbal behaviours from transcripts of video interactions:

Additional behaviours were scored using transcripts of the same six-minute segments described above. Behaviours coded included the following:

1. *Parent-initiated opportunity to respond, (including compliance) (OR):* This was defined as a parent provides opportunity for child to respond, (including opportunity to comply). This verbalisation is often posed as a question or command.

2. *Child appropriate, inappropriate or non-response (R+, R-, Rn):* This was defined as the child responding verbally or non-verbally to parent initiated opportunity to respond or comply (OR).

The behaviours were scored by coding all adult utterances that are opportunities to respond (OR) according to the definition above. With the transcript in hand, the video was then watched to observe the child's verbal and non-verbal responses to each OR. Their response was scored as either R+ for appropriate response, R- for inappropriate response, or Rn for no response. The results were reported as a percent of parent's OR followed by child appropriate, inappropriate and non-responses.

Simplified language: Several measures were used to assess the degree to which parents simplified their language. Using the same 6 minutes of transcript as before, starting at the time closest to 2 minutes and ending at the closest time to 8 minutes, measures of mean length of utterance, parents' words and words read from the picture book were obtained as follows:

3. *Mean Length of Utterance (MLU):* This behaviour was of interest because EarlyBird encourages parents to simplify their language and one way to simplify language is to reduce the length of utterances. MLU was calculated following these steps:

Choose enough consecutive utterances to have 100 completely intelligible, non picture-book utterances to analyse. If words are from the picture book, or if even one word in an utterance is not understood, that utterance is excluded from the analysis. Words that are unintelligible are transcribed as INDISTINGUISHABLE, or enclosed in square brackets. Then count the morphemes in each utterance, and add the number of morphemes for all 100 utterances. Finally divide by 100 to get the mean, or average. For a detailed description of how to count morphemes see Appendix 4.

4. *Mother's Words:* This behaviour was of interest because a previous evaluation of the EarlyBird programme (Hardy, 1999) reported a total word count of mother's verbalization as an outcome measure. To count mother's total words spoken all sentences with indistinct words in them and all sentences that include words that are unintelligible (these are transcribed as INDISTINGUISHABLE, or are enclosed in square brackets) were excluded. Also excluded was all text read directly form the picture book in the toy set, filler words (e.g. um, er, mmm), and part words (e.g. "good ca …" counts as one word).

   The following were counted:

   1. All words including letters (e.g. B.I.N.G.O. counts as 5 words), letter prompts (e.g. Ruh – prompting the word red) and numbers (1,2,3 etc.).
   2. Non-words that convey meaning in the context of play (e.g. 'Aghh' and 'Oh').
   3. Repeated words (e.g. no, no, no counts as 3 words).
   4. Words which are false starts, reformulations, or repetitions.
   5. All contractions (e.g. she's, he'll, they're, what's, she'd, we've, can't, aren't, let's, don't, won't) as ONE word. NOTE THIS IS THE OPPOSITE OF THE PROTOCOL FOR COUNTING MORPHEMES.
   6. Words that are directly adjacent to picture book extracts (e.g. It says "a bunch of bouncing brown basketball bugs" counts as 2 words).
   7. Count hyphenated words as individual words (e.g. no-no-no counts as 3 words).

5. *Words from Book:* Words that mothers read directly from the picture were counted separately. This involved counting each word from all text read from the picture book in the toy set. Hyphenated words were counted as individual words, (e.g. "big-mouth-bug" is 3 words).

Procedure

The families who volunteered for the in-depth evaluation study were contacted and appointments were made for observational recordings of each family at four different points in time. These times were as follows:

1. Pre-programme control (or baseline) 10 weeks before the start of the programme for the Auckland Group, and 4 weeks before the start of the programme for the Tauranga / Hamilton group.
2. Pre-programme (up to a week before the start of the programme).
3. Post-programme (within a week of completing the programme).
4. Follow-up (3 months after completion of programme).

During these sessions, parents were also given the four questionnaires outlined above. They were asked to fill them, as soon as possible and return them to the researchers in the prepaid envelope provided.

Before each recording session, at least 10 minutes was spent on helping everyone to relax, and get the families used to the presence of researchers and the cameras. The parents were then given a bag of toys and told to play with their child using the toys provided and asked to play as normally as possible under the conditions. The contents of the striped toy bag included a bug soft toy, a coloured plastic bouncy ball, wooden blocks inside a plastic bag, a plastic toy car and plane, a flap story book about bugs and a second striped toy bag.

At each visit, one camera was set up on a tripod while a second was hand held. The handheld video was used to capture the mother's face, while the tripod video camera was utilised to capture the child's face as much as possible.

Data Analyses

All questionnaire data was entered into SPSS, and repeated measures MANOVA of all scales and sub-scales were carried out the same as for the national study (Section 4 of this report). In addition correlational analyses were carried out in the same way as for the national study for the APQ stress and family subscales, and the FES and the PSI sub-scales.

Video segments were analysed as described above.

Results

Statistical analyses of the grouped data found few significant programme effects or intercorrelation between different measures. This may have been in large part a result of the small number of participants. For this reason group data is presented briefly, followed by more detailed analysis of individual families.

Analyses done to identify programme effects for the group x APQ scores, CARS-P scores, FES scores, and PSI scores.

As shown in Table 5.1 repeated measures ANOVA of total APQ scores showed a significant effect for time [F= 4.157 p< 0.05]. Overall the total APQ scores increase over time, suggesting that parents are improving in autism-specific parenting skills and knowledge as measured by the APQ. Paired T-tests revealed that the difference between baseline and pre-programme was not significant, but the difference between pre-programme and post-programme was significant, suggesting that there was a significant programme effect (rather than simply a maturation effect). This result is consistent with changes recorded in the larger national study.

Repeated measures MANOVA of the remaining measures, including subscales revealed only one significant effect: for the FES Control subscale. Further analyses (paired samples T-tests) showed that the significant within group difference was between levels of FES Control at baseline and pre-programme times [*t* (DF=6-2.52= p < 0.05]. During this time levels of FES Control increased, suggesting that families resorted to increasingly controlling modes of functioning. Following the start of the Earlybird programme changes on this measure are no longer significant, suggesting that EarlyBird helped to slow the escalating trend towards more controlling family functioning.

Table 5.1. Means and standard deviation for FES Control sub-scale at baseline, pre-programme, post-programme and follow-up times

Measure	Baseline		Pre-programme		Post-programme		Follow-up	
	mean	SD	mean	SD	mean	SD	mean	SD
APQ total	3.96		4.14		4.43		4.63	
FES C	4.71	1.11	5.57	1.27	6.14	1.49	5.75	1.98

Case reports

Family 1:

Andrew (all names have been changed to ensure confidentiality) was a 2 year 11 month old Pakeha boy with Autism and was rated as having severe autism symptoms on the CARS-P measure. Andrew lived with his mother, a former school teacher; his father, and younger sister. Andrew had limited content in his expressive speech, but used some phrases. He also had echolalic tendencies and was difficult to understand at times. According to his mother, Andrew understood 'key words' and appeared to 'listen in' on adult conversations. Prior to the programme, his mother had noticed a slight deterioration in his speech. Andrew's family had recently begun using the Picture Exchange Communication System (Bondy & Frost, 1994) to improve communication with him. Andrew had daily temper tantrums which involved hitting, kicking and head banging. His mother reported a strong desire for routine. Andrew had some imaginary play ability involving mostly cars, trains and telephones. He would try and join in games with parents, but rarely with other children, although he would play along side them.

Table 5.2: ***Andrew's questionnaire data***

Name: Andrew		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
APQ	1. Stress	2.00	1.67	1.00	3.00
	2. Knowledge & Understanding	3.75	5.25	4.75	6.00
	3. Behaviour Management	4.33	4.83	5.67	5.83
	4. Play	3.50	5.00	6.00	6.00
	5. Family Functioning	2.75	3.50	3.25	4.25
	6.Communication	4.40	4.40	5.60	5.60
	7.Confidence	3.00	5.67	5.67	5.33
	Mean APQ	3.56	4.37	4.67	5.22
CARS-P	A*	3.43	2.93	2.71	2.79
	B	3.64	3.36	2.29	2.79
PSI	PD	26.00	17.00	44.00	30.00
	PCDI	37.00	35.00	47.00	45.00
	DC	23.00	26.00	37.00	29.00
	Total	86.00	78.00	128.00	104.00
FES	1. Cohesion	7.00	7.00	9.00	8.00
	2. ARO	2.00	1.00	4.00	3.00
	3. Organizational	8.00	9.00	9.00	9.00
	4. Control	6.00	6.00	7.00	7.00

**Shaded areas on tables indicate low scales are desirable.*

Table 5.2.a: ***Andrew's observational and transcript data***

Observational Data		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
Parents	Turn-taking	1	2	0	0
	Following lead	0	2	1	0
Children	On-task %	100	72.73	100	75
	Initiations % int.	0	0	0	0
	Aversive % int.	8.33	9.09	2.78	16.67
Trans analysis	OR	44	43	40	36
	% R+	52.27	29.27	70.00	47.22
	% R-	15.91	14.63	2.50	13.89
	% Rn	31.18	56.61	27.50	38.89
	Parent ave. wait time	2.57	2.26	3.50	2.86
Lang analysis	1. Parent's Words	489	435	558	584
	2. Words from Book	0	0	0	0
	3. Total words	489	435	558	584
	4. Words per minute	81.50	72.50	93.0	97.33
	5. MLU	2.96	3.14	4.77	3.71

Andrew's parents' APQ subscores generally showed positive results, with increases in desirable behaviour for all dimensions (including 'Stress'), from pre-programme to follow-up. The exception to this was 'Confidence' which showed a mild decline at follow-up. Andrew's scores on both parts of the CARS-P showed a similar positive outcome, indicating a mild decline between pre-programme to follow-up, on perceived severity child symptoms and parental stress.

Andrew's parents' scores on the three subscales of the PSI were his most variable results. The three subscales scores, indicated that parental stress, perceived parental child interaction and difficult child, were generally lowest at pre-programme, rising quite dramatically at the post-programme assessment, before reducing slightly at follow-up; a pattern similar to the APQ Stress subscore. Andrew's FES scores remained relatively constant over time, although a notable feature was the low "ARO" subscores, which did improve slightly at the last two evaluations.

Little change was noted in Andrew's and his mother's observational and language analysis data, apart from a mild drop in "on-task" behaviour, and an increase in "aversive behaviour" between post-programme and follow-up.

The noticeable increase in "off-task" and "aversive" behaviour between post-programme and follow-up may have been due to Andrew waking from a nap in a bad mood, shortly before the observational recording began. Andrew's mother also reported that she felt quite stressed when the programme finished, trying to assimilate new information from the programme. This may help explain the increase in the "Stress" and drop in "Understanding and Knowledge" scores at pre-programme.

Family 2:

Brett was a 2 year 11 months old boy diagnosed with Autism, and was rated with mild to moderate autism symptoms on the CARS-P scale. Brett lived with his parents, and an older brother. The family moved house between post-programme and follow-up times. Brett had some speech, although it was limited in content, vocabulary, and had echolalic features. He also responded to language he understood. Brett would tantrum several times a day if he did not get something he wanted. He adapted relatively well to changes in routine, although he was more concerned about changes that effected him more personally such as a change in a favourite video and wearing certain clothes. Brett was able to play appropriately with toys. For example, he was beginning to push cars around, although at times he became fixated with their wheels. Brett was set to start part-time at a private kindergarten once his family completed the EarlyBird programme.

Table 5.3: ***Brett's questionnaire data***

Name: Brett		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
APQ	1. Stress	2.67	2.33	1.33	1.67
	2. Knowledge & Understanding	4.25	5.00	5.75	6.00
	3. Behaviour Management	4.80	5.67	5.67	5.83
	4. Play	5.50	6.00	5.50	6.00
	5. Family Functioning	4.50	4.50	4.25	4.75
	6.Communication	4.50	5.60	6.00	5.40
	7.Confidence	6.00	3.00	6.00	5.00
	Mean APQ	*4.56*	*4.74*	*5.07*	*5.07*
CARS-P	A	2.07	1.86	2.64	2.36
	B	1.43	1.43	1.86	2.36
PSI	PD	36.50	41.00	44.00	33.00
	PCDI	54.00	46.00	46.00	39.00
	DC	44.00	46.00	41.00	36.00
	Total	*134.50*	*133.00*	*131.00*	*108.00*
FES	1. Cohesion	7.00	7.00	6.00	6.00
	2. ARO	6.00	7.00	5.00	5.00
	3. Organizational	1.00	6.00	1.00	2.00
	4. Control	4.00	5.00	6.00	7.00

Table5.3.a: ***Brett's observational and transcript data***

Observational Data		**Baseline**[1]	**Pre-Prog**	**Post-Prog**	**Follow-up**
Parents	Turn-taking	0	0	1	0
	Following lead	1	3	4	2
Children	On-task %	100	83.33	100	88.89
	Initiations % int.	0	2.78	2.78	0
	Aversive % int.	0	0	0	0
Trans analysis	OR	13	2	20	14
	% R+	15.38	0	10.00	14.29
	% R-	0	0	0	14.29
	% Rn	84.62	100	90.00	71.43
	Parent ave. wait time	2.08	3.5	5.00	3.57
Lang analysis	1. Parent's Words	220[1]	202	258	201
	2. Words from Book	0	0	0	0
	3. Total words	220	202	258	201
	4. Words per minute	36.67	33.67	43.00	33.50
	5. MLU	1.97	2.39	2.34	2.00

[1] Both parents were interacting with the child in this video observation.

Brett's parents' scores on the APQ generally did not show much change over time, apart from mild increases in both "Confidence" and "Stress" between pre-programme and follow-up. Brett's parents also perceived the severity of his autism symptoms and their stress as increasing slightly as indicated the CARS-P scores, between pre-programme and follow-up. These findings contrasted with the three PSI subscores which all showed a general average decline for the same period.

Brett's parents' FES subscales results, did not suggest much change over the measured domains over time, except for "Control" which showed a small, but steady increase. Two notable features of the "Organisational" subscale were the very low scores for the baseline, pre-programme and follow-up assessments. These scores contrasted with a high score at pre-programme. Another notable feature was the relatively high "ARO" scores, which contrasted with most of the other families' low scores.

In the observational and transcript data, an increase in parent-initiated opportunities was evident, but this was not translated into a notable increase in positive child responses.

Brett's baseline data may have been influenced by having both parents present and interacting with him. For example, in this evaluation parent-initiated opportunities to respond totalled 13, in contrast to 2 at the following pre-programme evaluation.

Family 3:

Callum was a 4 year old Pakeha boy who had an Asperger Syndrome diagnosis with mild to moderate autism symptoms on the CARS-P measure. He lived with his mother, his step-father and an older brother. Callum's mother gave birth to another child between post and follow-up times.

Callum's mother reported that his spoken language was approximately age appropriate and that he also appeared to understand much of the information that was spoken to him and around him, including German which his grandfather spoke to him. He was also quite adaptable to changes in routine, although he still needed to have certain items, such as a favourite teddy nearby.

Callum was beginning to develop imaginative play skills, which included playing with dolls. He would also play ball with someone else although he would more commonly be on the periphery of a social activity. Callum had some mild right hemiplegia, for which he was receiving physiotherapy, as well as support from an education support worker at kindergarten.

Table5.4: ***Callum's questionnaire data***

Name: Callum		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
APQ	1. Stress	4.33	.	3.00	4.33
	2. Knowledge & Understanding	3.25	.	5.00	5.00
	3. Behaviour Management	3.17	.	4.17	4.33
	4. Play	3.00	.	5.50	4.00
	5. Family Functioning	4.75	.	3.00	5.00
	6.Communication	3.40	.	5.20	4.60
	7.Confidence	4.00	.	4.00	4.67
	Mean APQ	3.67	.	4.23	4.59
CARS-P	A	1.71	.	1.71	2.36
	B	1.62	.	1.50	1.86
PSI	PD	40.00	.	42.00	35.00
	PCDI	51.00	.	51.00	48.00
	DC	39.00	.	40.00	36.00
	Total	130.00	.	133.00	119.00
FES	1. Cohesion	8.00	.	9.00	8.00
	2. ARO	2.00	.	3.00	2.00
	3. Organizational	7.00	.	7.00	6.00
	4. Control	4.00	.	3.00	2.00

Table 5.3.a: ***Callum's observational and transcript data***

Observational Data		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
Parents	Turn-taking	0	3	1	2
	Following lead	1	2	0	1
Children	On-task %	91.67	87.88	54.55	100
	Initiations % int.	0	0	0	0
	Aversive % int.	0	0	30.3	2.86
Trans analysis	OR	10	24	25	17
	% R+	10.00	8.33	4.00	11.76
	% R-	50.00	4.17	0	23.53
	% Rn	40.00	87.50	96.00	64.71
	Parent ave. wait time	6.5	4.96	4.72	4.12
Lang analysis	1. Parent's Words	271	215	350	293
	2. Words from Book	11	0	25	37
	3. Total words	282	215	375	330
	4. Words per minute	47.00	35.83	58.33	55.00
	5. MLU	3.16	3.41	3.35	3.70

Callum's parents did not return pre-programme questionnaire data. His parents' APQ generally showed a slight but steady increase in all desirable behaviours, from baseline to follow up, except for stress which peaked at post-programme before dropping to baseline levels at follow-up. Severity of autism symptoms and parental stress as measured by the CARS-P showed a slight increase over time, while in contrast, the PSI subscales scores showed a slight decline from baseline to follow-up.

On the FES, "Cohesion" was consistently very high at 8 or 9, contrasting with the low scores of both the "ARO" and "Control" subscales, which showed minimal change over time. Callum's observational data showed high aversion rates at post-programme, which was supported by the lower 'on task' behaviour rate.

Callum's high aversion rates and lower rate of 'on-task' behaviour at post-programme may have been linked to his mother's advanced pregnancy. The slightly higher stress level as indicated by the Stress subscale of the APQ and the three PSI subscales scores may have tapped into this extra potential stress.

Family 4:

David was a 3 year old boy of Chinese ethnicity who lived with his mother, father, and an older brother. He had an Autism diagnosis with mild autism symptoms as measured on the CARS-P. David had minimal expressive language which was limited to a few echolalic words and phrases and frequently took his mother's hand to indicate his needs. David understood simple instructions in both English and Mandarin. He was adaptable to changes in routine but would regularly tantrum if he did not get what he wanted. David displayed some imaginative play ability such as 'feeding' his soft toys. He also took turns with another person when playing ball or with cars. David attended day care for three sessions a week.

Table 5.5: ***David's questionnaire data***

Name: David		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
APQ	1. Stress	2.67	3.33	3.67	3.33
	2. Knowledge & Understanding	1.25	3.00	6.00	4.00
	3. Behaviour Management	2.50	2.67	4.33	3.83
	4. Play	4.00	6.00	4.00	4.50
	5. Family Functioning	3.50	3.25	2.75	3.00
	6.Communication	3.80	4.20	4.40	4.20
	7.Confidence	2.33	4.33	4.67	3.67
	Mean APQ	2.81	3.59	4.30	3.78
CARS-P	A	1.86	1.64	1.86	1.71
	B	1.93	1.79	1.86	1.79
PSI	PD	32.00	31.50	34.00	31.00
	PCDI	35.00	41.00	42.00	39.00
	DC	23.00	26.00	27.00	26.00
	Total	90.00	98.50	103.00	96.00
FES	1. Cohesion	6.00	3.00	4.00	4.00
	2. ARO	1.00	2.00	2.00	2.00
	3. Organizational	4.00	5.00	4.00	2.00
	4. Control	6.00	8.00	6.00	7.00

Table 5.5.a: ***David's observational and transcript data***

Observational Data		**Baseline**[1]	**Pre-Prog**	**Post-Prog**	**Follow-up**
Parents	Turn-taking	No data	No data	No data	No data
	Following lead	1	3	4	2
Children	On-task %	100	100	100	100
	Initiations % int.	0	0	2.78	0
	Aversive % int.	22.86	8.33	0	0
Trans analysis	OR	6	1	2	16
	% R+	66.67	100	100	31.25
	% R-	0	0	0	0
	% Rn	33.33	0	0	68.75
	Parent ave. wait time	3.67	1	1.5	2.31
Lang analysis	1. Parent's Words	253[1]	104	246	281
	2. Words from Book	0	0	0	144
	3. Total words	253	104	246	422
	4. Words per minute	42.17	17.33	41.00	70.33
	5. MLU	1.85	1.60	1.55	2.08
	Phrases in Mandarin (% of total)	9.44%	35.29%	11.65%	5.00%

[1] *Both parents were interacting with child in this video observation.*

Five of the seven subscales scores of the APQ, "Stress", "Knowledge and Understanding", "Behaviour Management", "Communication" and "Confidence" peaked at post-programme, before slightly dropping off at follow-up, while the Play subscale scores for post-programme and follow-up were lower than that at pre-programme. David's CARS-P scores showing severity of symptoms and parental stress showed little change as did the PSI subscore scales. A noteworthy feature of the FES was the very low "ARO" subscale scores, and the slight but steady decline in the "Organizational" subscore.

David's aversive behaviour decreased notably from baseline to post-programme, and was not seen during the post-programme and follow-up observations. This decline could be associated with the development of his language which meant he was able to communicate more effectively and appropriately.

Transcript analysis showed a marked increase at follow up in ORs but these resulted in an increase in non-responses rather than positive responses. Language analysis showed a reduction in the parent's use of Mandarin over time. The use of one language may be of benefit to David.

The decline in "Play" and "Organisation" as measured by the APQ may have been influenced by David's mother's pregnancy and the family's moving house between post-programme and follow up. David's mother also made the comment that she found the programme useful in terms of providing information about autism, of which she knew little before the programme. This increase in understanding is reflected in the "Knowledge and Understanding" subscale, which went from 3 at pre-programme to 6 at post-programme.

David's "aversive behaviour" may also have reduced as a result of his language skills developing throughout the course of the programme, and the possible focus on using one language.

Family 5:

Eden was a 4 year old boy who lived with mother, father and an older sister who had Asperger syndrome. Eden had an Autism diagnosis with mild symptoms on the CARS-P scale. Eden had expressive speech skills that were limited in content, vocabulary and was echolalic. He also understood simple language and commands. Eden's mother reported although he had regular tantrums, he adapted relatively well to change in routines. Eden also had imaginative play skills which included putting toy people on trains and having them talk to each other. He also participated in social games such as playing scarecrow and flashcards. An Education Support Worker supported Eden for seven and a half hours per week at kindergarten.

Table 5.6: ***Eden's questionnaire data***

Name: Eden		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
APQ	1. Stress	2.33	2.00	2.33	1.67
	2. Knowledge & Understanding	4.75	4.25	6.00	4.50
	3. Behaviour Management	4.40	4.17	4.83	4.50
	4. Play	5.50	6.00	4.00	6.00
	5. Family Functioning	4.00	4.25	4.75	3.75
	6.Communication	3.80	3.60	4.40	4.00
	7.Confidence	4.67	5.67	4.67	5.33
	Mean APQ	4.15	4.15	4.56	4.19
CARS-P	A	2.07	2.17	2.29	2.23
	B	2.07	1.75	1.71	1.77
PSI	PD	24.00	24.00	20.00	22.00
	PCDI	42.00	34.00	35.00	36.00
	DC	31.00	29.00	33.00	30.00
	Total	97.00	87.00	88.00	88.00
FES	1. Cohesion	4.00	4.00	4.00	4.00
	2. ARO	2.00	2.00	3.00	2.00
	3. Organizational	4.00	3.00	4.00	3.00
	4. Control	5.00	5.00	6.00	4.00

Table 5.6.a: ***Eden's observational and transcript data***

Observational Data		Baseline	Pre-Prog	Post-Prog	Follow-up
Parents	Turn-taking	No data	0	2	0
	Following lead	No data	2	0	1
Children	On-task %	100	100	100	100
	Initiations % int.	0	2.78	2.78	0
	Aversive % int.	0	2.78	0	0
Trans analysis	OR	No data	18	18	12
	% R+	No data	50.00	38.89	50.00
	% R-	No data	22.22	33.33	0
	% Rn	No data	27.78	27.78	50.00
	Parent ave. wait time	No data	7.56	3.61	4.75
Lang analysis	1. Parent's Words	182	249	182	119
	2. Words from Book	0	0	102	63
	3. Total words	182	249	284	182
	4. Words per minute	30.33	41.50	47.33	30.33
	5. MLU	3.57	3.43	2.87	2.69

Eden's parents' APQ subscale scores showed little change over time, as was the case with the PSI subscale scores, apart from a general drop indicated in the total score between baseline and pre-programme. The same could be said about the FES scores, apart from a small drop in the 'control' subscale between post and follow-up. Eden's "ARO" scores over time remained low with minimum change.

In Eden's transcript data, Eden's mother showed a steady reduction in MLU, and her average wait time decreased over time.

Positive features noted, included a steady reduction in parental MLU over time. Although the programme generally encourages wait time, too much wait time may not be of positive benefit. Eden's mother's still had an average wait time of 4.75 at follow-up. Eden's mother has some experience of ASD, with her daughter having an Asperger Syndrome diagnosis.

Family 6:

Fred was a 3 year 6 month old Pakeha boy who lived with his mother, father, and two brothers (one older and one younger). He was diagnosed with Autism, with mild to moderate symptoms as rated by his parents on the CARS-P.

Fred had no speech and would lead adults by the hand to indicate his needs. Attempts had been made to teach him some sign language but with limited success. However, Fred was able to understand some basic commands. He frequently had temper tantrums, although his mother reported he was coping better with changes than he had done in the recent past. He had no imaginative play skills nor did he join in play activities with others. Before the programme, Fred was attending three different preschools/playgroup facilities for a total of 5 sessions.

Table 5.7: ***Fred's questionnaire data***

Name: Fred		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
APQ	1. Stress	3.33	4.00	2.67	2.67
	2. Knowledge & Understanding	3.50	3.00	No data	4.50
	3. Behaviour Management	3.83	3.00	3.83	4.33
	4. Play	3.00	2.50	4.00	3.50
	5. Family Functioning	5.25	4.25	4.00	4.00
	6.Communication	4.00	2.80	4.50	4.20
	7.Confidence	5.33	3.67	4.67	4.00
	Mean APQ	4.07	3.30	3.95	4.00
CARS-P	A	2.71	3.14	2.79	3.07
	B	2.86	2.46	2.61	3.14
PSI	PD	.	41.00	37.00	34.00
	PCDI	.	35.00	31.00	25.00
	DC	.	38.00	29.00	27.00
	Total	.	114.00	97.00	86.00
FES	1. Cohesion	9.00	7.00	9.00	8.00
	2. ARO	3.00	1.00	3.00	4.00
	3. Organizational	8.00	8.00	8.00	9.00
	4. Control	3.00	5.00	5.00	5.00

Table 5.7.a: ***Fred's observational and transcript data***

Observational Data		**Baseline**	**Pre-Prog[1]**	**Post-Prog**	**Follow-up**
Parents	Turn-taking	0	0	0	0
	Following lead	0	0	0	0
Children	On-task %	2.78	0	0	20.59
	Initiations % int.	0	0	0	0
	Aversive % int.	80.56	100	16.67	5.89
Trans analysis	OR	48	18	5	19
	% R+	4.17	5.56	0	5.26
	% R-	47.92	27.78	20	0
	% Rn	47.92	66.67	80	94.74
	Parent ave. wait time	2.38	3.78	3.46	3.16
Lang analysis	1. Parent's Words	385	202	95[2]	350
	2. Words from Book	4	0	0	0
	3. Total words	389	202	95	350
	4. Words per minute	64.83	33.67	16.52	60.87
	5. MLU	3.11	2.59	4.24	2.93

[1] Fred indicated he was hungry with PECS card and then ate for final four minutes of the video clip.

Parental increases in stress was noted in the 'Stress' subscores, and the CARS-P scores, although this was not indicated in the PD of the PSI. The family's "ARO" subscore showed the most change in the FES.

Fred's observational data showed a noticeable decrease in Fred's "aversive behaviour" and an increase in "on-task" behaviour. Positive changes were also reflected in the drop in negative child response, although this resulted in more non-responses than in an increase in positive response.

There was some difficulty in getting enough film of Fred. For example, during post-programme recording, Fred indicated with a PECS card that he wanted to eat, and then proceeded to do so for 4 minutes. Although disruptive to recording, this indicated a significant improvement in his communication skills, and a corresponding reduction in aversive behaviour. Fred's mother reported that she had begun using PECS with some success.

Family 7:

Greg was a 3 year six month old Pakeha/Malaysian Indian boy who lived with his mother, father, and an older sister. Greg was diagnosed with Autism and his parents rated him as having mild autism symptoms. Greg had limited speech. His language was also echolalic and at times difficult to understand, and he frequently led his parents to objects he wanted. Greg had repeated tantrums in which he sometimes bit, kicked, and hit people. He loved to play with cars and trucks; and loved watching favourite videos. Greg's mother reported some engagement in imaginative play. He would put cars in garages, people in houses, as well as setting up furniture appropriately in a doll house. Greg tended to play alongside rather than with other children. He attended day care for 15 hours per week.

Table 5.8: ***Greg's questionnaire data***

Name: Greg		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
APQ	1. Stress	5.00	4.33	1.33	4.33
	2. Knowledge & Understanding	5.00	4.50	4.00	5.25
	3. Behaviour Management	4.33	4.33	5.17	5.67
	4. Play	3.00	3.50	4.00	5.50
	5. Family Functioning	4.75	4.25	3.00	5.50
	6.Communication	4.20	4.00	5.20	4.60
	7.Confidence	6.00	4.67	5.00	5.00
	Mean APQ	4.63	4.26	4.15	5.15
CARS-P	A	2.00	2.07	3.14	3.00
	B	1.64	1.71	2.36	2.29
PSI	PD	41.00	42.00	44.00	49.00
	PCDI	43.00	43.00	36.00	39.00
	DC	39.00	39.00	32.00	32.00
	Total	123.00	124.00	112.00	120.00
FES	1. Cohesion	8.00	8.00	9.00	8.00
	2. ARO	2.00	2.00	5.00	1.00
	3. Organizational	9.00	9.00	9.00	9.00
	4. Control	5.00	6.00	8.00	8.00

Table 5.8.a: ***Greg's observational and transcript data***

Observational Data		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
Parents	Turn-taking	0	No data	0	0
	Following lead	1	No data	1	0
Children	On-task %	80.65	58.33	96.88	66.67
	Initiations % int.	0	0	0	0
	Aversive % int.	0	0	3.13	3.7
Trans analysis	OR	6	No data	13	6
	% R+	16.67	No data	0	33.33
	% R-	0	No data	7.69	16.67
	% Rn	83.33	No data	92.31	50.00
	Parent ave. wait time	2.17	No data	3.46	1.83
Lang analysis	1. Mother's Words	155	No data	166	154
	2. Words from Book	15	No data	0	0
	3. Total words	170	No data	166	154
	4. Words per minute	28.33	No data	27.6	25.6
	5. MLU	1.99	No data	2.30	1.71

Greg's parents' questionnaire results did not have any notable patterns. In general his APQ subscores showed mild increases from pre-programme to follow-up, excluding "Stress" which increased at post-programme before decreasing slightly at follow-up to pre-programme levels. Increase in parental stress was also indicated by the PD subscore of the PSI. Finally Greg's family showed very high scores in "Cohesion" and "Control" in the FES. The ARO subscore apart from a notable increase at post-programme remained comparatively low.

Greg's observational data was for the most part incomplete for the pre-programme evaluation due to technical difficulties. No notable changes were discerned through time for the variables measured, with variation between scores over time.

Despite the fact that no changes were picked up in scores over time, Greg's parents generally made positive comments about the programming, finding the OWL system and the subsequent reduction of language useful. They also reported an increased understanding in the part antecedents play in subsequent behaviour. For example, they became aware that their son's sensitivity to light could influence his behaviour at the supermarket.

Family 8:

Henry was a 3 year six month old Pakeha boy who lived with his mother, father, and two brothers (one older and one younger). Henry had an Autism diagnosis with mild to moderate symptoms as rated on the CARS-P scale. Henry's spoken language had echolalic features which were sometimes difficult to understand. It was also limited in content and phrases. Henry was able to understand basic instructions although these often needed to be repeated. Henry did not commonly have tantrums and had relatively few problems with changes in routines. He had a keen interest in trains and had some limited imaginative play skills.

Henry was involved in a behavioural treatment programme (12 hours per week), and had access to a private speech-language therapist, private occupational therapist, an education support worker at preschool (4.5 hours out of 8 hours), and a cranial osteopathy therapist. His mother reported he was beginning to learn turn-taking through his behavioural programme and his educational support worker targeted this skill specifically at preschool.

Table 5.9: ***Henry's questionnaire data***

Name: Henry		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
APQ	1. Stress	3.33	5.33	3.00	4.67
	2. Knowledge & Understanding	4.25	5.75	4.50	6.00
	3. Behaviour Management	4.17	3.50	5.17	4.00
	4. Play	4.00	4.50	6.00	6.00
	5. Family Functioning	4.00	4.50	2.75	4.25
	6.Communication	4.20	3.80	5.60	5.40
	7.Confidence	5.67	6.00	4.00	5.67
	Mean APQ	4.22	4.59	4.48	5.00
CARS-P	A	2.00	1.93	1.79	2.07
	B	2.17	1.86	1.50	1.93
PSI	PD	42.00	48.00	47.00	51.00
	PCDI	35.00	35.00	45.00	41.00
	DC	48.00	45.00	53.00	40.00
	Total	125.00	128.00	145.00	132.00
FES	1. Cohesion	8.00	8.00	7.00	9.00
	2. ARO	6.00	6.00	7.00	6.00
	3. Organizational	4.00	7.00	6.00	5.00
	4. Control	4.00	4.00	5.00	6.00

Table 5.9.a: ***Henry's observational and transcript data***

Observational Data		**Baseline**	**Pre-Prog**	**Post-Prog**	**Follow-up**
Parents	Turn-taking	0	0	1	0
	Following lead	0	0	0	0
Children	On-task %	87.5	97.22	100	100
	Initiations % int.	0	0	2.78	0
	Aversive % int.	0	0	0	0
Trans analysis	OR	36	49	33	40
	% R+	63.89	61.22	45.45	75.00
	% R-	5.56	0	15.15	0
	% Rn	30.56	38.78	39.39	25.00
	Parent ave. wait time	2.69	2.67	2.97	2.48
Lang analysis	1. Parent's Words	409	378	457	291
	2. Words from Book	90	135	21	160
	3. Total words	499	513	478	451
	4. Words per minute	83.17	85.50	79.67	75.17
	5. MLU	3.80	3.95	3.32	1.96

On the APQ, Henry's parents' "Play" and "Communication" subscales showed moderate change. Parental stress showed an increase at post-programme level as indicated by the APQ subscore and PSI "PD" subscale score. On the FES the "Control" subscale showed an increase between pre-programme and follow-up. Generally, there was no change over time seen in the observational and transcript data, except for MLU which showed a positive decrease. Henry's mother said she had made deliberate attempts to simplify her speech.

Discussion

The current study had two primary related aims. The first purpose was to find out whether there was a change over time due to participation in the EarlyBird programme, as reflected in a range of measures including, but in additional to those used in the national study. These included both psychometric and observational measures. This type of multi-method evaluation was not possible with families participating in the national evaluation due to the large number involved. Statistical analyses performed on the APQ subscales showed that participation in the programme resulted in an improved outcome for the children and their families over and above any maturational effects, supporting the national study findings. The only other significant effect found was an increase in the FES Control subscale over the periods baseline and pre-programme.

Secondly, the present study was interested in providing validation of the APQ measure which had been specifically developed for evaluating the EarlyBird programme within a New Zealand context. For this purpose the CARS-P (which was used in the national study), PSI, FES and observational and transcript measures were utilised. Statistical analyses of the data provided limited significant findings. There was no evidence to support a correlation between the APQ Stress subscale and the CARS-P-b subscale as had been shown in the national study. The only significant correlation found was between the APQ Family Functioning subscale and the FES Control subscale.

The small sample size with large between subject differences may explain the limited statistically significant findings. As a result it was decided to look for any additional patterns or points of interest on a single-case basis, on both quantitative measures as well as qualitative data, including interviews with parents to gain more information.

A disturbing finding was that all the parents who participated in the in-depth study had clinically significant levels of stress (a score exceeding 90 on the PSI / SF) at some point in time during the course of the evaluation. Five of the eight parents show clinically significant levels of stress at every point of data-collection. For the majority of parents who had high levels of stress the programme was associated with some reduction in stress levels at least at follow-up. In most cases stress levels remained at unacceptably high levels though. It is difficult to imagine that this does not have negative implications for the parents and / or their families long term.

Interesting results were found on several subscales of the FES. Families who took part in the study tended to have high “Cohesion” scores which indicates that family members tend to have high levels of concern, commitment and provision of support for one another. For families with a young person with developmental disabilities, high family cohesion has been found elsewhere to be associated with a sense of self-reliance and competence (Nihira, Mink & Myers, 1981, cited in Moos & Moos, 1994). High cohesion was also found to be one of the best predictors for psychosocial adaptation at home and school (Mink, 1986, cited in Moos & Moos, 1994). Moreover, high family cohesion in families with children with autism and communication impairments was associated with better-quality parenting, less maternal depression, and better marital adjustment (Bristol, 1987, cited in Moos & Moos, 1994).

Several of the families also scored very high on the FES "Control" subscale which assesses the degree to which families uses set rules and procedures to run family life. A significant finding of this study was the increase of "Control" scores prior to the programme. In relation to youth with developmental disabilities, high family control has been associated with poorer school adjustment (Nihira, Mink & Myers, 1981, cited in Moos & Moos, 1994), while other research has suggested that for this same population, being brought up in a control-orientated and disengaged family meant an increased chance of poorer personal and social adjustment, and less self esteem (Mink, Blacher & Hihira, cited in Moos & Moos, 1994). Research to date does not show what is normative for families with young children with ASD. It maybe that for children of this age and disability, high control is appropriate as it reflects the needs of parents to implement routines of behaviour management and self-care skills training.

A pattern of consistently low FES "ARO" subscores was also evident, indicating families may have had limited opportunities for active participation in social and recreational activities. For some of the parents in this group, this extended to challenges in carrying out simple tasks outside the home such as shopping. Brett's mother commented about the tantrums he would have if he was not allowed to hold round fruit such as melons, when at the supermarket. Similarly, Callum's mother reported difficulties in shopping in places that had fans because Callum disliked the sound they made.

This pervasive sense of autism controlling their lives was a main theme in one qualitative study in which parents of children with severe autism talked about how much of their daily life and energy was focused on meeting the needs and demands of their child with autism. One important way it impacted on both parents and siblings was in the lack of time and resources to pursue their own interests (DeGrace, 2004). There was also the sense of being "robbed" of happy and satisfying experiences that bonded "normal" families together, such as going on holiday or attending a birthday, with one parent commenting that sometimes it was not worth the trouble (DeGrace, 2004).

Several factors may explain the limited and/ or consistent change seen in the observational measures of the present study. One possibility was that parents did not change. A second factor was that sampling was too restricted in that observations were too few and too short in duration. One limitation of having few observations was that one "bad" day could bias results. For example, Andrew woke up in a bad mood just before post-programme recording took place. In addition, observations were limited to one situation, whereas the child's behaviour might have varied between settings. However due to constraints set down by programme managers, limited resources and not wanting to further impose on families, longer multi-observations in varying settings were not possible.

Additional stress on families may also have interrupted change. Callum's mother had a baby during the course of the programme, while David's mother was heavily pregnant at the follow-up assessment. Andrew's mother noted that participation in the programme brought its own type of stress in her attempts to integrate and put into practice information and strategies that she had gained. This may have partially explained her higher stress levels at post-programme, which were short-lived, as her stress scores had dropped by follow-up.

There was also the potential impact of most of the eight children being relatively high-functioning, and accordingly with high rates of "on-task" behaviour from the beginning. Moreover some parents had already, or were currently receiving other assistance.

Despite the appearance of limited or consistent change, and similar to MacNiven's (2002) findings, the parents who participated in Earlybird programme were positive about their experience. One recurring theme that came through in interviews with parents, was how EarlyBird had increased their knowledge and helped them to better understand their child. This increased understanding meant they were better able to pre-empt and manage challenging behaviours, using practical strategies. As one parent stated, "EarlyBird has given us hope; a light at the end of the tunnel." All said they would recommend the programme to others and stated how reassuring it was to meet other parents who were going through similar challenges, and being able to provide support for each other as well as exchanging ideas.

SECTION 6

Introduction to Section Six:

NAS EarlyBird Programme Uptake Study

This section presents the up-take study. Presented are a brief introduction, the method, results, and a brief discussion of our findings. This study has been previously reported to the Ministry of Health, who funded it. It is included here so that it can be read within the context of the whole evaluation, and so that we can include its findings in the overall discussion. Approval from the Auckland University Human Participants Ethics committee was granted for this section of the work independently from application that covered the work reported in the previous three sections.

Section Six:

NAS EarlyBird Programme Uptake Study

Introduction

It is reasonable to assume that a government funded programme should, in principle, be available to all parents of children with autism who would benefit from it. In order to establish the value of the EarlyBird programme for parents of children with autism in New Zealand it is important to consider not only whether the programme delivered has a positive effect on those who participate in it, but also who has access to the programme.

Factors which may predict families' under-use of early intervention services include membership of a minority cultural or linguistic group, low family income, parental unemployment, and living in a rural area (Zhang & Bennett, 2003). These factors lead into the three main issues to be considered in a programme uptake study:

- *Issues of equity:* Is the programme selective in terms of culture, social class, or the resources needed to attend?
- *Issues of relevance:* Is the programme perceived by parents to be relevant to their needs?
- *Issues of access:* Is the programme inaccessible to some families because of where they live?

The current study was undertaken in conjunction with the NZ EarlyBird efficacy evaluation by the same authors, and aimed to determine the rate of uptake of the EarlyBird programme by target families, and to identify potential barriers to participation. Specific research questions considered were:

1. What proportion of families who have children with ASD between the ages of two and four find out about the EarlyBird programme?

2. Are there any differences in terms of SES, ethnicity, or place of residence (rural versus urban) among those who attend EarlyBird?

3. Of those families who find out about EarlyBird, what determines their decision to participate in the programme and what are the reasons that some families do not participate?

4. Are there other barriers to accessing the EarlyBird programme arising from identification of autism and obtaining a diagnosis?

5. Are there barriers to participation particular to ethnic minority groups?

Method

The data reported in this study comprises of telephone interviews, and three focused interviews with representatives from ethnic minorities. Ethical approval for the procedures undertaken was obtained from the University of Auckland Human Ethics Committee prior to the commencement of this study.

Participants

The total number of families who participated was 77. Seventy three of these were families who had a child aged between two and six years old with a confirmed diagnosis of autism at the time of the study. These were families whose child was between two and four years old at the time when the EarlyBird programme was established in New Zealand, or who were currently eligible to participate in the EarlyBird programme. Also participating were six families whose children with autism were aged between 7 and 21 years old at the time of the study. Participants were contacted using the methods described below.

Telephone interviews

These were undertaken with a total of 77 families who were sent information and consent forms relating to the study via three sets of mail-outs, a snowballing technique, presentations and personal contact with ethnic minority groups. In snowballing a first contact is selected and interviewed and then asked to suggest other interviewees, and so on. This sampling method is acknowledged as being useful for identifying minority groups within communities (Spring, Westermeyer, Halcon, Savik, Robertson, Johnson, Butcher, & Jaranson, 2003). Information relating to each group is presented below.

<u>Group One:</u>

As part of a questionnaire development activity undertaken within the main EarlyBird study all members of Autism NZ nationwide (1782 recipients) were contacted. Consent forms for the current study were included and member families whose child with autism was between two and six years were invited to respond. Twenty responses were received. In 2001 Autism NZ estimated it had 90 member families whose child with autism was under 5, and 502 families with primary school age children. As there is no more recent information it is assumed that the characteristic of ANZ members in 2003 was similar to the 2001 membership, thus the actual number of potential participants contacted was a subset of 592.

<u>Group Two:</u>

Families in this group were contacted by including information and consent forms relating to the study with the Autism NZ national newsletter mail-out. Forms were distributed to all members of the National Association who were living in Auckland, Tauranga and Nelson and whose child with autism was between the ages of two and six years eleven months old at the time of the mail-out. Auckland was chosen as representative of a large urban centre, Tauranga a small urban area with semi rural outlying areas, and Nelson a rural area with remote dwellings. A total of 168 forms were distributed.

<u>Group Three:</u>

In recognition of the bias toward Autism NZ members through the above distribution mechanisms an attempt at snowballing the participant pool was undertaken. During the course of the telephone interview respondents were asked whether they knew of other families who were not members of Autism NZ to whom they could pass on information about the study. Eleven people responded that they could do this. It is not known how many (if any) responses resulted from this.

Group Four:

In a second attempt to contact families not associated with Autism NZ information about the study was posted to 144 families (121 families in Auckland, one family in Tauranga, and 22 families in Nelson) through the Needs Assessment Teams in these areas. The information was distributed to all families who had contact with the teams whose child on the autistic spectrum was aged between two and six years eleven months. It was recognised that there would be considerable overlap between this pool of subjects and those contacted through the earlier Autism NZ mail-out.

Group Five:

Within Auckland Maori, Pacific and Korean populations were specifically targeted. Participant information sheets and consent forms were translated into Korean and Samoan. Information on the study was distributed to Korean families through Milal (the Korean autism society), and the Hanouri Korean church. Pacific Island families were contacted through the South Auckland Special Needs Group, and Taikura Trust (Auckland NASC). Attempts were made to access Maori families through Porirua paediatrician, Campbell Lodge, Kari Centre, and via contacts in Tauranga and Northland.

Due to difficulties in recruiting respondents from these minorities the target age range of two to six years was abandoned, and all families who could be contacted were encouraged to return consent forms. The result was that families with children up to 21 years of age were recruited in these groups. The older children were primarily from Korean families where migration patterns are such that families arrive in NZ when their child with autism is school age. Approximately 25 forms were distributed to Korean families with seven returns, approximately 45 to Pacific Island families with three returns and approximately 35 to Maori families with five returns.

In depth interview group:

Due to the low success rate in recruiting ethnic minority groups into the telephone survey a further attempt to explore cultural barriers was devised. Focused interviews were undertaken with representatives from Maori, Pacific Island and Korean communities using open ended questions to find out more about barriers to participation. These interviews involved four Pacific Island participants, one Korean participant, and two Maori participants all of whom are parents of children with autism. Interviewees were identified through the study’s advisory committee, the South Auckland Special Needs Group and Milal (the Korean autism society).

Table 6.1: Demographic Summary of 77 participants interviewed by telephone

Demographic Summary (N77)		
Current Age of Child	Mean	5y 6m
	SD	3y 2m
	Median	5y 0m
Age Range	2 – 3 years	33.77%
	4 – 6 years	57.14%
	7 years and above	9.09%
Place of Residence	Urban	80.9%
	Rural	19.1%
Family Composition	Nuclear	85.5%
	Single Caregiver	7.9%
	Extended	6.6%
Ethnicity of Child	Total European	77.7%
	NZ European	71.1%
	Other European	6.6%
	Korean	10.5%
	Maori	6.6%
	Pacific Is	3.9%
	Other	1.3%
Number of Children in family	1	17.1%
	2	61.8%
	3	21.1%
Socio-Economic Status (n=57) * (as per Elley-Irving Index)	1	19.3%
	2	50.9%
	3	15.8%
	4	7.0%
	5	3.5%
	6	3.5%

** Participants who were recruited in group one were not asked about their occupation.*

Measures

A standardised telephone survey questionnaire was developed by the researchers. The survey was designed to elicit information which would answer the research questions outlined on page 3, and which could be administered by telephone in 15 minutes or less. The survey also incorporated a question (item 9) through which it was hoped to gain access to families who were not members of Autism NZ.

A semi structured interview schedule was devised using open ended questions to gain information about barriers to uptake for Maori, Pacific Island and Korean families. These interviews took approximately 60 – 90 minutes to complete with each respondent.

Procedure

Telephone Interviews –

Information sheets and consent forms relating to the study were distributed to a total of 1782 + 312 = 2094 potential participants. A total of 98 responses were received (90 consent forms and 8 forms to indicate prior response), of these 77 respondents were able to be contacted for telephone interview.

The questionnaire was administered by telephone to those families who consented to be part of the study, and with whom telephone contact was able to be made (three attempts were made to telephone each person who returned a consent form). This stage of the study began in May and ended in mid November. The consent form included the option of nominating an interview language. The questionnaire was administered in English (70 participants) and Korean (7 participants). Interviews were administered by one member of the research team (CB), one Maori postgraduate student (TB), and one Korean postgraduate student (GK). Qualitative data in the form of comments made by participants was recorded during the telephone interviews. A summary of the qualitative comments relating to each research question is included in relevant sections of this report.

Data from the questionnaire was analysed and summarised primarily using descriptive statistics to answer the research questions. Some respondents chose not to answer one or more of the questions.

Focused Interviews –

Families were approached by one of the researchers (CB), the study was explained in person and permission to audio-tape the interview was sought. All of the caregivers approached (7) agreed to participate. Focused interviews were administered in English by one of the research team (CB). These interviews were audio-taped and transcribed. Participants were forwarded a copy of the transcription to check prior to the presentation of the current report.

Results and Discussion

Analysis of telephone interviews

> *"What proportion of the families who have children with ASD between the ages of two and four find out about the EarlyBird programme?"*

Of the total sample 93.5% had heard of Autism NZ and 87% had heard of EarlyBird. Of those who had heard of EarlyBird 94% were members of Autism NZ and 6% were non-members. Of those families who had heard of Autism NZ, 91.7% had also heard of EB, of those who had not heard of Autism NZ 20% had heard of EB.

Table 6.2: Percentage of those who have heard and not heard of Autism NZ who have heard about EarlyBird

	Heard of Autism NZ	Not Heard of Autism NZ
Heard of EarlyBird	91.7%	20%
Not Heard of EarlyBird	8.3%	80%

Of those who reported being members of Autism NZ 95.6% had heard of EB. This compared with an awareness rate of 22.2% for non Autism NZ members.

Table 6.3: Percentage of members and non-members of Autism NZ who have heard about EarlyBird

	Members of Autism NZ	Non Members of Autism NZ
Heard of EarlyBird	95.6%	22.2%
Not Heard of EarlyBird	4.4%	77.8%

By ethnicity those within the total sample who had heard of the EB programme were comprised of European 79.1% (NZ European 71.6 and Other European 7.5%), Maori 7.5%, Pacific Island 4.5%, Asian 7.5% and Other 1.5%. Of those who reported they had not heard about the programme 66% were NZ European, and 33.3% were Asian. Within each ethnic group 89.8% of the Europeans (NZ Europeans 88.8% plus Other Europeans 100%) who responded had heard of EarlyBird, 100% of Maori, 100% of Pacific Island, and 62.5% of Asian respondents.

Participants who had heard about the programme were asked the question *'How did you hear about EarlyBird?'* Respondents reported having heard about EarlyBird through Autism NZ newsletters, packs and personal contact with Autism NZ staff, from friends, through Group Special Education (GSE), via Healthcare sources, through CCS and through a teacher.

Table 6.4: Responses to the question 'How did you hear about EarlyBird?'

How heard about EarlyBird (n59)*	Frequency	Percentage
Autism NZ (newsletter, pack, personal contact)	37	62.7%
GSE	11	18.6%
Friends	4	6.8%
Healthcare Sources (diagnostician, professional, hospital	4	6.8%
CCS	2	3.4%
Teacher	1	1.7%

** Some participants reported more than one source.*

Examples of qualitative comments recorded for this question:

> Social worker through CCS.
>
> Paediatrician mentioned it in his follow up letter.
>
> Info centre at Starship had notice about EarlyBird.
>
> Diagnostician and SES.
>
> Heard early last year through another parent. Thought it was too late by time heard as my child was almost 5 [child diagnosed at 2.4, now 5].

Some people commented that they had not heard of EarlyBird, but felt they should have done so:

> Special Ed should be telling parents, some people are struggling.
>
> Why didn't Starship tell us about it? General paucity of information – didn't find out for years about Taikura Trust or Spectrum Care, and then only by chance through a contact [child diagnosed at 4yrs, now 6.5].

It would seem from this data that being a member of Autism NZ gives families a much higher chance of hearing about the EB programme, suggesting that general levels of promotion of the programme to newly diagnosed families through sources other than Autism NZ may be insufficient. Qualitative comments indicate that promotion of the programme through other sources may be fragmented and inconsistent, suggesting that more publicity for the programme may be required to reach all potential participants. Those included in the current study who were least likely to have heard of the programme were European and Korean families. Pacific Island, and Maori families were more likely to have heard about it, (but less likely to have participated – see figures below). One potential confound in these figures is the fact that, despite extensive efforts to widen the sample, all of the Maori and Pacific Island families who responded were members of Autism NZ. It is likely that there is an overlap between those families who are not members of the Association and those who are unlikely to be responsive to research involvement. As information and consent forms for this study were translated this is unlikely to be solely a language issue.

> *"Are there any differences in terms of SES, ethnicity, or place of residence (rural versus urban) among those who attend EarlyBird?"*

Of people who had heard of EarlyBird 40.9% had done the programme and 59.1% had not done so. Within our sample there were no significant differences in terms of SES or place of residence between those who attend EarlyBird and those who do not.

Table 6.5: Results of ANOVA to calculate differences by SES and location for families who have completed EarlyBird

Done EarlyBird			Not Done EarlyBird		Difference
SES	Mean	2.42	Mean	2.41	.985
	SD	1.12	SD	1.37	(Not significant)
Location	Frequency Urban	20	Frequency Urban	26	.912
	Frequency Rural	55	Frequency Rural	7	(Not significant)

By ethnicity those who had completed the EarlyBird programme were European 88.9% (NZ European 81.5%, Other European 7.4%), Maori 7.4%, Pacific Is 0%, Asian 0%, and Indian, Arabian and Hispanic (Other) 3.7%.

Table 6.6: Percentage of respondents from each ethnic group who had completed EarlyBird

Ethnicity	Done EarlyBird
European	88.9%
Maori	7.4%
Pacific Island	0%
Asian	0%
Other	3.7%

As noted above awareness of EarlyBird within Pacific Island families in our sample was 100%, and for Korean families 62.5% . That there was a nil rate of uptake in both Pacific Island and Korean families suggests there may be particular issues for these groups around participation. These issues are explored in more detail in section 3.2.

> *"Of those families who find out about EarlyBird, what determines their decision to participate in the programme, and what are the reasons that some families do not participate?"*

Participants were asked *'When you heard about it, what did you think of the EarlyBird programme?'* Most families reported feeling positive and wanting to do EarlyBird when they first heard about it. Other comments were: didn't really look into it, wished I'd heard earlier / I found out too late for my child to attend, unsure about it – worried about amount of work involved adding to existing pressures, keen but wait time was too long / it isn't offered in my area yet, times EarlyBird is offered (daytime sessions) didn't suit due us, didn't really understand what EarlyBird was, didn't like the look of it, thought it couldn't hurt, liked idea of support, wary about the idea of videotaping.

Table 6.7: Responses to the question 'When you heard about it, what did you think of the EarlyBird programme?'

What did you think of EarlyBird ? (n73)*	
Sounded good, wanted to do it	52%
Didn't really look at it	11%
Wished I'd heard earlier, my child was too old	9.6%
Worried about the work involved adding to my stress	5.5%
Keen but the wait time in my area was too long	5.5%
Times didn't suit us	5.5%
Didn't really understand what it was about	4.1%
Didn't like the look of it	2.7%
Thought it couldn't hurt	1.4%
Liked the idea of the support aspect	1.4%
Wary about videotaping	1.4%

** Some participants expressed more than one idea*

Examples of qualitative comments recorded for this section:

> Liked the idea of knowledge and also support aspect.
>
> I wanted it but my husband wasn't sure about the commitment. But fantastic programme [have now completed EarlyBird].
>
> It can't hurt. Some of it I will already know [found out about it 1 year after diagnosis].
>
> Desperate for anything, really keen.
>
> Wish I had known about it 2 years ago [doing EarlyBird now, child diagnosed at 3yrs now 5yrs].
>
> Didn't become aware of it until he started school [child diagnosed at 3.6, currently 6.5].
>
> Wanted to do EarlyBird but sounded like hard work. So buckled under by stress hard to commit then told wait time for course would be at least a year and maybe not even then.
>
> Interesting, but wary about the videotaping. Understood that it was for early diagnosis, would have liked to do, but it was too late.
>
> Didn't bother going to introductory session as I had been told the programme was run during the day and my husband can't take time off work. Evening programmes would be better.
>
> Sounds pretty good. Times and days don't fit with my kids (one just started school, one three year old). Looking to it in the future.
>
> I am waiting for EarlyBird to get to Tauranga. I'm quite upset about the wait, not so worried for us but I'm really worried about others because all of this waiting is absurd especially considering early intervention in autism is crucial and waiting for a programme is just wasting time.

There were 39 participants (50.6% of the sample) who had heard about EarlyBird and chose not to attend. These participants were asked "What were your reasons for not participating?"

Participants who responded to this question reported that non-participation was due to not having time to attend, difficulty in attending sessions due to child care, the programme not being offered in their area, their child too old by the time they found out about EarlyBird, being too busy with / making good progress with other interventions, the length of wait time for a programme to be run in their area, not being offered an introductory session, finding out too far down the track – after already having done a lot of research themselves and therefore feeling that they would get limited value from EarlyBird, still grieving and therefore not ready when the programme was offered, being turned down for the course because of not being able to attend all of the sessions, and difficulties in getting to the venue.

Table 6.8: Participants responses to the question 'What were your reasons for not participating?'

What were your reasons for not participating? (n30)	
Don't have time	16.6%
Difficulty in attending sessions due to child care	13.3%
Not offered in my area	13.3%
Child too old by the time I found out	10%
Making good progress with other interventions	10%
Length of wait time	10%
Not offered an introductory session	6.7%
Found out too far down the track	6.7%
Still grieving (not ready) when the programme offered	3.3%
Couldn't get to all the sessions	3.3%
Difficulties in getting to venue	3.3%
Lack of empirical evidence for EarlyBird	3.3%

Examples of qualitative comments recorded for this section:

> Not suitable for busy mum especially because of finding childcare.
>
> Not available in area as need more numbers.
>
> Wasn't being run in Auckland. Frustrating as I really wanted something, L was 4 years old. By the time it came to Auckland felt like it was too late.
>
> Didn't qualify. Started school in October, diagnosis in December.
>
> We do an intensive ABA programme 25 hours per week through Autism Partnership. We have had such incredible results through this over the past 18 months that we were reluctant to participate in a programme that had no empirical research to show its value. Had we not been doing ABA we probably would have given EarlyBird a go.
>
> She's been making good progress in what she is doing so don't feel a need to be doing EarlyBird.

> Didn't feel we needed to learn about autism. A good idea for parents with a new diagnosis but we felt we were further along than that. If they had one for school age kids I would go, in the past 2-3 months I felt motivated to do something.
>
> Didn't go to an introductory session as I didn't have any information about such a session.
>
> When being told about it was still grieving so didn't really take it all in.
>
> We were offered a place on the course, went through arranging childcare but couldn't get to one session due to family commitments. Let organiser know and was told couldn't attend the course in that case. (Someone later said we should have just not turned up to the session as often people don't go to all of them but I thought we were doing the right thing by letting them know). My child was coming up to 4 then. We were offered the next course which is the one running currently but it was too late for our son. Angry and disappointed about this.

One of the barriers mentioned above was the wait time for the programme. Participants who had done an introductory session were asked. 'How long did you have to wait to do the introductory session or programme?'. Of the sample 66.6% reported a wait time of 1-3 months, and 12.1% a wait time of 3-6 months. A further 12.1% waited 6-12 months, and 9.1% waited for more than a year.

Table 6.9: Participants responses to the question "How long did you have to wait to do the introductory session or programme?"

How long did you wait to do EarlyBird? (n33)	
1-3 months	66.6%
3-6 months	12.1%
6-12 months	12.1%
Over 12 months	9.1%

Participants who experienced a wait were asked 'How did you feel about the wait time?' In response 18.8% said they didn't notice the wait, 40.6% said were satisfied with the wait time, 25% said it could have been better, and 15.6% were very frustrated by the length of wait.

Table 6.10: Participants responses to the question 'How did you feel about the wait time?'

How did you feel about the length of wait? (n32)	
Didn't notice	18.8%
Satisfied	40.6%
Could have been better	25%
Frustrated	15.6%

The data reported above indicates that most families, when they find out about EarlyBird, feel positive about the programme and are keen to participate. While some have concerns about the programme when they hear about it these concerns may not necessarily prevent people from going on to participate in EarlyBird. At least one participant reported going on to do the programme and enjoying it. Possibly a somewhat elevated proportion of unenthusiastic initial reactions to a programme such as EarlyBird, which targets parents at a distressing and confusing time (diagnosis), is to be expected. However, of the families who reported concerns about EarlyBird on first hearing about it 15% did not participate in the programme.

From data on reasons for non-participation five main issues arise as factors, which may act as barriers:

1. It seems that there are difficulties in running EarlyBird frequently enough to cater to demand across all parts of NZ.
2. Limited awareness of the programme may result in families being unable to attend due to their child being too old when they find out about the programme.
3. Families of children with autism are busy and frequently carry a high stress load. Some families have initial reservations relating to the programme as regards the amount of time, work or stress it might involve.
4. Difficulty in obtaining childcare may affect families ability to commit to the programme.
5. That the daytime sessions offered by the programme may make attendance difficult for some families.

As there need to be six families registered for a programme to be started some families in smaller towns and rural areas may wait for a long time (and children may grow too old for the programme) before they can participate. Difficulties cited also touched on the problem of getting commitment from families without definite dates for them to plan toward, and the concurrent need for Autism NZ to have sufficient families committed to warrant running the programme. Comments seem to suggest also that there is a 'critical' time for EarlyBird after which its usefulness may be reduced as families undertake their own research and networking (albeit possibly in a less efficient way, and with all the frustrations of sifting through to relevant materials).

These constraints highlight one area in which EarlyBird may not translate well to NZ conditions, that is, a considerably lower population density than the UK. One solution, to reduce the number of families required, or to have a maximum wait time after which a programme will be run regardless of whether the full complement of families are available, is currently being addressed through a recent Autism NZ adaptation of EarlyBird. A condensed version of the programme is now being run in rural areas, catering for 3 - 6 families. This is a good example of the way in which the programme can be sensitively adapted to NZ requirements.

In regard to wait time, it should be noted that although a long wait time was reported as a reason for not participating by some respondents, not all families who had long wait times were deterred and many completed the programme. Some of these families, although they had been very unhappy about the length of wait, made positive comments about the programme itself.

For some families there was sadness that they had not heard about EarlyBird soon enough after diagnosis to participate. This ties in with the need for a more systematic method of disseminating information about the programme to newly diagnosed families. The way in which this is done however is an issue which needs careful consideration, as evidenced by the caregiver who reported that she experienced a time of grieving during which she did not feel ready to do the programme. Several families report not having really looked at or taken in the information about EarlyBird. It is to be expected that at diagnosis, a time during which parents report massive information overload, a leaflet or poster is likely to be neglected.

For a number of families the requirement to attend daytime sessions was unsuitable. This is likely particularly to affect families where both parents are working, and those families with young children for whom daytime childcare is often more difficult than evening and weekend when family and friends may be able to assist. It is possible that lower income families, and larger families, including Maori and Pacific Island families may be more affected by these factors. Giving a choice of evening or weekend session times for EarlyBird would seem to be a useful step toward reducing barriers.

> *"Are there other barriers to accessing the EarlyBird programme arising from identification of autism and obtaining a diagnosis?"*

The mean age of diagnosis for the total sample was three years three months (SD one year 10 months). Of the sample 62.5% reported their child's diagnosis came from a Paediatrician, 10.4% a Psychiatrist, 20.8% a Psychologist, and 6.5% Other (for example Multi-Disciplinary Team). There were no significant differences between age at diagnosis and the clinician type who gave the diagnosis.

Table 6.11: Breakdown of diagnosis by clinician type

Who made the diagnosis? (n77)	
Paediatrician	62.5%
Psychiatrist	10.4%
Psychologist	20.8%
Other (e.g. Multi-Disciplinary Team)	6.5%

Of the total number of respondents 52.6% said they had no problems with getting a diagnosis, 27.6% reported some problems, 18.4% reported lots of problems and 1.3% made other comments. For those people who reported problems the most common was a long wait for diagnosis, other difficulties were reported as limited knowledge of ASD by professionals, and complications due to co-morbid diagnosis (for example ASD symptoms being masked by co-morbid ADHD).

Table 6.12: Participants responses to the question 'Did you have an difficulties getting a diagnosis?'

What were the problems with diagnosis?	
Long wait	73.3%
Limited knowledge from professionals	26.7%
Co-morbidity	20%

An ANOVA analysis showed no significant differences by location (urban / rural) in the type of clinician from whom a diagnosis was obtained, or the age at which a diagnosis was obtained. There is insufficient data from Maori and Pacific Island groups to undertake a similar analysis by ethnicity, however the qualitative data reported in section 4.0 (page 21) of this report suggests that these groups have a later age of diagnosis, and that many or most children from these groups remain undiagnosed until they start school.

Examples of qualitative comments recorded for this section:

> Wasted a few months as no one wanted to say it was autism.
>
> Fought to get taken to SLT. Referred to paediatrician who wouldn't give a hard diagnosis. Getting the MDT diagnosis took a long time.
>
> Always knew there was a problem. Ongoing difficulties, kept being told nothing wrong. ADHD and autism, ADHD masked symptoms.
>
> Waited about 6 months for an appointment. Had already had older son diagnosed.
>
> Plunket and Developmental Assistance people ignored my asking for help.
>
> Child psychiatrists non-existent in Starship. Waited so long for an appointment, then conflicting opinion. Starship would be better to just refer people private.

> Problems getting a referral. Thought something wrong but doctor said normal 2year-old behaviour. Had to push hard [diagnosed at 3.10].
>
> Heaps [of problems] – every time went to the doctor told he was special. Back and forth to psychologist and paediatrician. Psychologist said thought ASD when first saw but didn't say [annoyed about this].
>
> Long drawn out battle to get [diagnosis] encompassing inadequate recognition of symptoms, personality differences with professionals, and isolation of area she lives in, and professional's limited knowledge of autism [summary of one page of notes from conversation on diagnosis problems].

Although the majority of parents did not report any problems in obtaining a diagnosis, those people who reported having had problems were often quite distressed about the amount of potential early intervention time that had been wasted. One theme evident in the qualitative comments was a feeling from parents that professionals are reluctant to use the label autism. This seems to reflect an understandable reticence on the part of clinicians concerned not to hand out false positives in diagnosis, and an equally understandable frustration on the part of parents who know something is 'not right' but without a diagnosis have no validation of their concerns, and no way to start looking for solutions.

Analysis of focused interviews

"Are there barriers to participation particular to ethnic minority groups?"

Two Maori women, one Samoan woman, one group of three Pacific Island women (two Samoan, one Tongan), and one Korean man were interviewed. The main themes arising from the focused discussions are reported for each ethnicity.

Maori –

- The cost of visiting a doctor may delay diagnosis in Maori families due to reticence about taking a child to the doctor unless there is obvious physical illness.
- There is a general lack of recognition of developmental disorders within the culture. This means that behaviour may be interpreted as naughtiness and parents told by older relatives that they are not doing a good job with discipline.

  > *"Good for me that they [EarlyBird] gave a lot of information on how autism isn't just naughtiness."*
  >
  > *(Maori mother who had completed EarlyBird)*

- Shame or guilt on the part of parents may prevent them from seeking help.
- Maori mums tend to be younger and may be less aware of normal developmental milestones. They may not have older family members around to point out a child's late speech, or other delays in development.
- Families tend to be bigger and parents both working.

Pacific Island –

- There is a general lack of awareness of developmental disability within the culture. There is no term or recognition in the culture for the concept of autism.

> *"...the ma'i concept it's a real general type concept and it includes developmental disorder, physical handicaps, intellectual. It's just such a wide word, it could even mean pregnancy. It's quite a blanket term for lots of ... so if a child has autism or ADHD or something it's like well he's ma'i or she's ma'i."*
>
> *(Individual interview)*

- Lack of recognition of developmental disorders means that behaviour may be interpreted as naughtiness and parents told by older relatives that they are not doing a good job with discipline.

> *"...for example they could just think that their child is being naughty, and so that is sometimes where the harsh discipline might come in. They don't realise that there is something wrong with the child, especially in autism because they look so normal".*
>
> *(Individual interview)*

- Shame or guilt on the part of parents may prevent them from seeking help.

> *"I think there is a sort of a traditional belief that if a child is not normal it could be a type of curse, or supernatural causes and one common one is that the parents have done something wrong to their parents"*
>
> *(Individual interview)*

- Parents are often both working and have larger families and less time to observe or focus on child's difficulties with language etc. This may lead to later diagnosis.

> *"I also think like the social type things like the parents might be working long hours, bigger families, you know, you might tend to miss these sorts of things like the developmental points that they are supposed to follow." "because a lot of Pacific Island families are low income parents have to work longer hours, bigger families, commitments to church, commitments back to the islands especially financial commitments and they work longer hours so maybe there is less energy if they do suspect that something is up to you know do something about it"*
>
> *(Individual interview)*

- Language can be a barrier, both to awareness and to participation in the programme.

> *Especially for non-NZ born Pacific Island parents, language can be a barrier. Possibly running the programme with Pacific Island facilitators could be one way to help with this.*
>
> *(Focus group)*

- There is a cultural norm of respecting the 'expert', and not questioning authority. This may affect diagnosis and also mean that parents feel unable to 'educate' teachers about what their child's needs are.

> *"... and lack of education, and just that authority thing ... like they are too scared to ask people that they see are in authority, and also with diagnosis its not like for them to just like pick up something. They wait for a doctor or a teacher to say that perhaps something is wrong. So I reckon that a lot of kids probably are picked up when they get to school ... especially the less severe cases".*
>
> *(Individual interview)*

- Cultural values – don't make a fuss, accept things as they are.

> *"From a Christian belief as well – it's God's will. They've been given this child for a reason. So there is acceptance perhaps".*
>
> *(Individual interview)*

- Concerns about being videotaped.

> *People were uncomfortable with idea of being videotaped. Didn't want to have a videotape of their child being shown to a new group of people.*
>
> *(Focus group)*

- Difficulties due to the times of EarlyBird sessions.

> *Many people in the group said that they would find it too hard to get two people along to daytime sessions since parents are busy during the day with work and childcare.*
>
> *(Focus group)*

- Feeling uncomfortable with home visits.

> *Some families in the group said they would be too busy at home to have trainers coming into the house for home visits, and might feel uncomfortable having strangers visiting.*
>
> *(Focus group)*

- Thoughts on EarlyBird and its appropriateness to Pacific Island families.

> *"It could fit with families that are educated here, that maybe have one or two children, where the parents are motivated to do it. But I think it would be quite difficult if English is your second language and all those other things that we mentioned – finding the time, energy to follow it through, I think there would be a few challenges."*
>
> *(Individual interview)*

Korean –

- Many Korean families arrive in New Zealand when their child with autism is ready to start school hoping for better educational opportunities in NZ.

> *"I thought the education was better than in Korea. Now, I'm not sure because, Korea has a lot of chance to get some special education for some autistic [children]".*
> *"...autism was quite rare in Korea. When my boy was six years old, someone [diagnosed] him with some sort of disease. ... But people didn't know what autism was. And then I thought, when we were in Korea, that for my son's education, we would have to go overseas".*

- There may be a sense of shame and guilt on part of parents.

> *"But also, in the past, twelve or fourteen years ago, that kind of thing used to be the parents' fault. That's the shame for the parents. That mindset is still around. But education makes a little difference".*

- Language is a barrier.

> *"Do you think there are any particular barriers for Korean families in accessing early intervention?"*
> *"Yeah, most people can't speak the language. Language is a problem."*

- Korean families like to stay with what is familiar.

> *"So do you think that that's a cultural thing that Koreans tend to like to stay with what's familiar?"*
> *"That's it. That's specially. We're all the same religion - Korea is under the same religion. Japan is different - Japan has approximately ten or fifteen religions. China has more, more, more religions in there. But in Korea, there's only one religion. That makes them isolated."*

- Families are very busy.

> *"... they're very, very busy. Parents are, in the father's case, usually they'd work from seven until eleven. I used to work very hard as well. His mother had to look after the other child. To look after an autistic child as well, it's very, very [BIG? – indistinct on tape]. It couldn't go on. Having to stay with him at home - it was impossible".*

There are a number of themes in these interview data which run through the three groups. All reported ideas within the culture about disability, and children with challenging behaviours, that may lead to shame or guilt on the part of parents. These feelings may be a barrier to parents getting a diagnosis, and thus to accessing the EarlyBird programme. This notion relates to a second theme; a lack of awareness within Maori and Pacific Island cultures of developmental disability as a diagnosis, and of early signs that may indicate the need for professional assessment. These two themes feed into a common thread of later diagnosis for Maori, Pacific Island families, often not occurring until a child reaches the school setting, and to a similar barrier relating to the age of the child with autism for Korean families currently in NZ. Migration patterns within this group have been such that many children with autism arrive in this country as they approach school age – their parents hoping for better educational opportunities here. Thus families from all three cultures are likely to be ineligible for EarlyBird due to their child's age.

Another potential barrier for all three cultures is a busy family life. For Maori and Pacific Island families there may be more children than in the average European family, parents are often both working, and there is often also a big commitment to church and community activities. In Korean families parents often work long hours. These issues may result in limited ability to attend programmes such as EarlyBird, particularly if only daytime sessions are offered.

In addition to these general points there are issues specific to each group. In Maori families there is the report of the expense of doctor's visits potentially delaying diagnosis, this factor may also apply to Pacific Island families on low incomes. Pacific Island women reported finding the idea of being videotaped, and having trainers visit their homes as barriers to participation in EarlyBird. These are both standard components of the current programme which would be difficult to change; however, some consideration needs to be given to these issues if Pacific Island families are to be encouraged into EarlyBird. A further concept which is foundational to EarlyBird, is that of the parents holding knowledge which they then use to advocate for, and to actively seek out the best interventions for their child. This concept seems to be at odds with Pacific Island beliefs about the role of the expert, and the role of the extended aiga / whanau in care of the child. Finally there are language barriers for, in particular, Korean families, and for some Pacific Island families.

In minimising these barriers it will be necessary for more extensive consultation to be carried out within Maori, Pacific Island and Korean communities. Each community will have its own ideas with which solutions might start to be formed. Within the focused interviews some suggestions that came from Pacific Island women regarding reducing barriers to EarlyBird for Pacific people were:

1. Publicity to raise general awareness of autism within the Pacific Island community, possibly using older respected people within church and local groups as educators.

2. Developing the EarlyBird concept into more of a community based programme where the emphasis is less on the nuclear family and more on involving and educating wider family, the kindergarten or language nest, and community groups to support the child with autism and their family.

3. Providing evening and weekend sessions of the programme.

Some of these ideas might also be useful as a starting point for discussions with Maori and Korean groups on suitable adaptations or alternatives to EarlyBird.

Conclusions and Recommendations

A group of 77 caregivers of children with autism were interviewed by telephone, and four focused interviews with representatives of Maori, Pacific Island and Korean communities were undertaken. Although the size of the sample, and the small number of respondents recruited from ethnic minority groups in particular, means that caution must be exercised in generalising the findings of this study, the quantitative and qualitative data collected suggest a number of themes which may influence uptake of the EarlyBird programme in NZ.

1. Data from this study suggests that within Autism NZ membership there is high awareness of the EarlyBird programme, indicating good promotion of the programme within the organisation. However it does seem that publicity about the programme through sources other than Autism NZ may be fragmented and inconsistent. More systematic publicity of the EarlyBird programme through diagnostic services, schools and professionals working with children with autism would be beneficial.

2. Comments seem to suggest that there is a ‘critical’ time for EarlyBird after which its usefulness may be reduced as families undertake their own search for services. Ensuring that families hear about EarlyBird and have access to the programme within this critical period is important. New Zealand’s lower population density creates additional problems in providing a timely intervention. One solution, to reduce the number of families required, or to have a maximum wait time after which a programme will be run regardless of whether the full compliment of families are available, is currently being addressed through a recent Autism NZ adaptation of EarlyBird.

3. For some families the requirement to attend daytime sessions is a barrier to participation in EarlyBird due to work and family commitments. It is possible that lower income families, and larger families, including Maori and Pacific Island families may be more affected by these factors. Giving a choice of evening or weekend session times for EarlyBird would be a useful step toward reducing barriers.

4. For Maori, Pacific Island and Korean families there appear to be specific barriers to accessing EarlyBird. Late diagnosis, or having arrived in NZ with an older child, means that EarlyBird is not available to these families. A programme aimed at families with school aged children would be useful to these groups, and to families whose children are now over seven (i.e. were diagnosed prior to the introduction of EarlyBird into NZ).

5. Initiatives aimed at reducing the age of diagnosis for Maori and Pacific Island families would maximise the opportunity for uptake of the programme by these groups. Parental and community awareness of early signs of developmental delay, and of autism may encourage families to look for assistance earlier.

6. Some adaptation of EarlyBird, for example offering sessions run by culturally appropriate facilitators to address language barriers for Korean and Pacific Island people, or moving toward more community focused programmes for Maori and Pacific Island families may also encourage participation. There is a need for ongoing research into Maori, Pacific Island and Korean perspectives on culturally appropriate early intervention services for autism.

SECTION 7

Introduction to Section Seven:

Overall Summary and Conclusions

This section presents an overall discussion of all the findings from the various projects that make up this evaluation. It attempts to integrate and synthesise the findings from all the studies reported, and discuss them in the context of the EarlyBird programme in New Zealand and the extant literature. Discussion with advisory groups and key stake holders, as well as comments from the EarlyBird parents, have contributed to our final conclusions. This section concludes with a list of recommendations.

Section Seven:

Overall Summary and Conclusions

The aims of this project were:

1. To develop a set of outcome criteria based on the theoretical literature around early intervention in autism, and the stated goals and objectives of the EarlyBird programme.
2. To evaluate the EarlyBird programme in light of these criteria and report on the maintenance of outcomes over time.
   a. In terms of the processes involved in the delivery and up-take of the programme.
   b. In terms of immediate, mid-term, and long-term direct (parent behaviours and attitudes) and indirect outcomes (child outcomes).
3. To establish how effective the questionnaire developed in the pilot study is in assessing programme outcomes, and produce a revised and validated tool for measuring the effectiveness of the EarlyBird programme, and
4. To investigate to what extent the EarlyBird programme is visible and accessible to those who would benefit from it.

Broadly the purpose of this study was twofold: to develop a questionnaire that can be used in ongoing evaluations of this and similar programmes, and to assess the effectiveness of EarlyBird in bringing about desirable changes with a New Zealand cohort.

This report was structured around five distinct research activities that were designed to meet the aims outlined above:

1. The EarlyBird Project – Literature Review
2. The Questionnaire Development
3. The National Study
4. The In-Depth Study
5. The NAS EarlyBird Programme Uptake Study

The literature review identified principles of effective early intervention for families with autism, and confirmed in general that the approach taken in the EarlyBird programme is in line with current best practice. It is generally considered important to provide training for parents of children with autism, and that such training should address the issues targeted in the Earlybird curriculum (i.e., informing parents, and providing them with strategies for improved interactions, facilitating play, and managing behaviour). Furthermore, a structure of delivery that includes opportunity for peer support and normalisation of the experiences of parenting a child with autism is likely to have additional benefits, such as a reduction in stress.

The literature review also helped identify outcome measures, and informed the development of both the logic model for the evaluation, and the seven dimensions assessed by the Autism Parenting Questionnaire (APQ). The questionnaire development resulted in a final 25-item questionnaire (APQ) with good construct validity (the seven conceptual sub-scales emerged as factors), and which proved sensitive to change, making it suitable as a pre-post-measure of programme effectiveness. This instrument, together with the accompanying manual, is now sufficiently developed to have been adopted for use in the UK. An ongoing evaluation of the EarlyBird programme in the UK, and an ongoing evaluation of the New Zealand programme are currently in progress using this instument. In addition to evaluating the effectiveness of the UK programme, and continuing to assess the effectiveness of the New Zealand programme, this work will allow further assessment of the reliability and validity of the APQ with a much larger sample. This should increase the usefulness and attractiveness of the APQ as an outcome measure for the effectiveness of the EarlyBird and other, similar programmes.

The primary purpose of the national and the in-depth studies was to provide data to assess the effects of the EarlyBird programme. Both studies were informed by the logic model, which identifies factors that may impact the effects of the EarlyBird programme as well as possible short-term, intermediate, and long-term outcomes for the programme, and the relationship between these factors.

The results of these two studies showed significant gains in APQ scores (total score and most sub-scale scores) associated with participation in the EarlyBird programme. Furthermore many of these gains were maintained, or there was continued improvement at follow-up. This suggests that over the time period of this study the responding parents improved significantly on the measures Knowledge, Communication, Behaviour, and Stress, as assessed by the APQ. Triangulation of the data from the national and in-depth studies supports the assertion that the observed changes were a result of participation in the EarlyBird programme. In addition there was some significant improvement in one aspect of family functioning in that the statistically significant rise in levels of Control (the extent to which a family used set rules and procedures to run family life) was slowed during and following the EarlyBird programme. Children from families with high levels of Control are thought to be at risk for poor personal-, social-, and school- adjustment, as well as lower self-esteem. The observed significant reduction in the rate at which levels of Control were increasing in these families is therefore potentially a highly beneficial outcome, not only for the children with autism, but also for their siblings. Further research into the effects of children with developmental disabilities (including autism) on family functioning in general and their siblings specifically is indicated.

The results summarised above support our logic model. There is a clear distinction between the short-term and intermediate outcomes as predicted by the model. The changes were differentially detected through the serial administration of the APQ. Some of the factors tapped by the APQ (Knowledge, Communication, Play and Behaviour) were shown to be more direct or immediate outcomes, as predicted. A change was observed over the course of the programme between pre- and post- programme. The improvements on other factors (Stress, Confidence and Family Functioning) proved to be indirect (intermediate and long-term) outcomes. Significant changes on these measures were not observed until follow-up time (3 month after completion of the programme. It would be valuable to test the external validity / generalisability of this finding in future research.

The findings of these studies indicate good treatment integrity in that the programme was delivered consistently across trainers. Participants in the programme receive a comparable service throughout the country. Furthermore the data indicate that the condensed version of EarlyBird, in which the same content is delivered to smaller groups of parents over a period of four weeks instead of six, does not significantly compromise treatment outcomes. These results should be interpreted with some caution though, because the sample was relatively small. The benefit of the condensed version of the programme are that EarlyBird can be delivered to smaller or more remote communities, and reduced wait-times in these places. Ongoing evaluation of the programme, especially where it is adapted or changed in any way, is indicated.

Results of between group differences by age indicate that the age of the child at the start of the programme does not affect outcomes significantly. In addition the programme is enjoyed by the parents who participate. Overall these results suggest that the EarlyBird programme as it is currently delivered in New Zealand leads to increases in autism specific parenting skills and decreases in stress levels for participating parents regardless of type of programme or group.

While overall EarlyBird has proven to be beneficial for the participants, several limitations have been noted. Despite the fact that NAS UK approved delivery of the condensed programme in New Zealand (a first), elements of programme delivery are still strictly prescribed. Data for our uptake study suggest that further adaptations may be required to enhance the applicability of the programme in New Zealand such that it becomes equally acceptable and accessible to diverse cultural groups.

During the course of the programme stress levels for participating parents increased. Parents reported that it is difficult to meet the requirements for participation and to organise for both parents (or two care-givers) to commit to attending the course between the hours of 10 am and 3 pm on a week-day. The rationale for running the programme at that time of day is to provide the parents with the opportunity for some social interaction over lunch. This peer support is seen as a critical part of the programme. It is also conceivable that a strict requirement such as this selects only the more committed and motivated parents, and thus increases the chances of the programme being effective. However, it probably also discriminates against parents with limited resources or social support. While the short-term rise in stress levels in participating parents may not be of great concern, the moral and ethical questions around fair and equitable distribution of resources and opportunity require careful consideration.

Whilst attempting to deal with issues of treatment integrity through detailed specification of both curriculum and delivery is laudable, a downside to this is a possible inability of the programme to adapt to local requirements, or to develop in light of advances in the empirical research.

The following recommendations for the future delivery of EarlyBird and associated research arise:

- Continued delivery of the EarlyBird programme in New Zealand with ongoing evaluation, especially if the programme is adapted or modified in any way.
- Continued trialing and further validation of the APQ.
- Further research on the effects of a child with autism on family functioning and educational outcomes for siblings.
- Adapting the programme to better meet the needs of the New Zealand population, which is characterized by cultural diversity and communities in geographically isolated locations.
- Promoting the integration of EarlyBird with other services. EarlyBird may be a very useful first step in terms of services for families with children with autism. Ideally it should be part of an integrated and seamless range of services and interventions for children with autism and their families from early childhood through to adulthood.
- This study represents a step beyond the work done by Hardy and Macniven in terms of developing valid and reliable outcome measures to measure beneficial changes in parents and children as a result of the EarlyBird programme, but more work is still needed on valid measures for language and video analysis.

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SECTION 8

Appendices

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Appendices

Appendix 1:

Criteria for Autistic Disorder from the DSM-IV-TR (American Psychiatric Association, 2000).

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1) and one each from (2) and (3):

  1. Qualitative impairment in social interaction, as manifested by at least two of the following:

     a. marked impairment in the use of multiple non-verbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.

     b. failure to develop peer relationships appropriate to developmental level.

     c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest).

     d. lack of social or emotional reciprocity.

  2. Qualitative impairments in communication as manifested by at least one of the following:

     a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).

     b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.

     c. stereotyped and repetitive use of language or idiosyncratic language.

     d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

  3. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

     a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.

     b. apparently inflexible adherence to specific, non-functional routines or rituals.

     c. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).

     d. persistent preoccupation with parts of objects.

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Note. From American Psychiatric Association (2000, pp. 75). Copyright 2000 by the American Psychiatric Association

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Appendix 2:

Ethics Forms

EarlyBird Project

Participant Information Sheet – National Study

Dear EarlyBird Participant,

We (Angelika Anderson, Dennis Moore, Fred Seymour and Christina Birkin) are a team of researchers from the University of Auckland. We have been contracted by the Ministry of Education to investigate the effectiveness and acceptability of the EarlyBird Programme in New Zealand. This investigation will include both a large scale national study, and a small scale in-depth study. This information sheet relates to the **national study**.

In the national study we hope to collect information from all parents involved in the EarlyBird programme during 2003 and analyse it both before, and at two points in time after the programme to find out what effect EarlyBird participation has on families. With your permission the EarlyBird trainers will allow us to use the information that they collect during the programme itself, such as your application form, evaluation sheets etc. We would also like to collect some extra information on the level of stress you experience as the caregiver of a child with ASD, and on the sort of difficulties your child has in day to day life. The additional information that we gather from you will be in the form of a questionnaire, and we anticipate that filling this in will take about 30 minutes of your time on each of three separate occasions. After completion of the study information on the findings of this research will be made available to you if you wish it.

All the information we collect will be confidential and neither your name, nor your child's name will be used in any report. You may withdraw from the study at any time, and may withdraw any information traceable to you up to two weeks after the conclusion of the EarlyBird programme you are participating in without giving a reason. You are under no obligation to participate. Participation is purely voluntary. Non-participation in this research will not affect your participation in the EarlyBird programme in any way. If you wish to participate please let us know by filling in the attached consent form and posting it in the enclosed stamped envelope.

If you have any queries or wish to know more please do not hesitate to contact us:

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For any queries regarding ethical concerns please contact:

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EarlyBird Project

Participant Information Sheet – In-Depth Study

Dear EarlyBird Participant,

We (Angelika Anderson, Dennis Moore, Fred Seymour and Christina Birkin) are a team of researchers from the University of Auckland. We have been contracted by the Ministry of Education to investigate the effectiveness and acceptability of the EarlyBird Programme in New Zealand. This investigation will include both a large scale national study, and a small scale in-depth study. This information sheet relates to the **in-depth study**.

In the in-depth study we hope to collect detailed information from a small sample of parents involved in the EarlyBird programme during 2003 and analyse it both before, and at two points in time after the programme to find out what effect EarlyBird participation has on families. As well as the data to be collected in the national study (i.e. the information you will be supplying to EarlyBird in the form of application forms and questionnaires) we will be collecting videotape data, and extra information on family and parental stress (using the Parent Stress Index). We will also be asking participants in this in-depth study to provide telephone contact details so that we can carry out telephone consultations. These consultations will address issues of your child's behaviour which you find problematic, and which will be tailored to your needs. Videotaping of you and your child will take place in your home for one hour before and after completion of the programme, and the additional survey information we will collect will take about 60 minutes of your time on three separate occasions. After completion of the study information on the findings of this research will be made available to you if you wish it. To be involved in this in-depth study you will need to also have given your consent to be involved in the national study.

All the information we collect will be confidential and neither your name, nor your child's name will be used in any report. You may withdraw from the study at any time, and may withdraw any information traceable to you up to two weeks after the conclusion of the EarlyBird programme you are participating in, without giving a reason. You are under no obligation to participate. Participation is purely voluntary. Non-participation in this research will not affect your participation in the EarlyBird programme in any way. If you wish to participate please let us know by filling in the attached consent form and posting it in the enclosed stamped envelope.

If you have any queries or wish to know more please do not hesitate to contact us:

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EarlyBird Project

Participant Information Sheet – Trainers

Dear EarlyBird Trainer,

We (Angelika Anderson, Dennis Moore, Fred Seymour and Christina Birkin) are a team of researchers from the University of Auckland. We have been contracted by the Ministry of Education to investigate the effectiveness and acceptability of the EarlyBird Programme in New Zealand. This investigation will include both a large scale **national** study, and a small scale **in-depth** study.

In the national study we hope to collect information from all parents involved in the EarlyBird programme during 2003, and in the in-depth study we hope to collect more detailed information from a small sample of parents. Information gathered from both of these groups will be analysed both before, and at two points in time after the programme to find out what effect EarlyBird participation has on families. Data to be collected in the national study will be the information already gathered through EarlyBird in the form of application forms and questionnaires. For the in-depth study we will also be collecting videotape data, and extra information on family and parental stress (using the Parent Stress Index).

We are asking for your help in gathering the required information from participants on one or more of the EarlyBird courses you are running in 2003 who have given their consent to participate in the evaluation process. Helping us will mainly involve doing only what you would normally do in the way of information gathering, but with the addition of making this information available to the research team. In the case of the one or two families in the in-depth study we would also ask you to distribute some additional forms to the parents, and to encourage them to fill these in and return them directly to us in the postage paid envelopes provided. We anticipate that this additional responsibility will take no more than 15 minutes of your time. After completion of the study information on the findings of this research will be made available to you if you wish it.

All the information we collect will be confidential. You are under no obligation to participate. Participation is purely voluntary. If you are willing to participate please let us know by filling in the attached consent form.

If you have any queries or wish to know more please do not hesitate to contact us:

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Appendix 3:

Treatment integrity – description of process, and results

1. Monitors will together review all
    - Session evaluations,
    - Home visit evaluations,
    - Video taped footage,
    - Trainer's home visit notes,
    - Post programme and follow up questionnaires
    - for all new Trainers for at least their first two groups.
2. A standard review chart (appendix 1) will be used to record information (positive, neutral or negative) fed back in the evaluations and questionnaires about the Trainers, the presentation of the Programme, and noting specific comments about the Trainers.
3. All home visit tapes and home visit notes will be viewed by the Monitors for the first two groups taken by new Trainers.
4. Random spot checks of the Programme delivery (i.e., calling for a Trainer to video tape the delivery of a particular group session for review by the Monitors) will be required from every trainer during the delivery to their first two groups, and then only as required (e.g., after a long break from delivery or if there are comments from the evaluation forms that raise concern).
5. Following review each Trainer will receive a copy of their monitoring forms and opportunities to discuss these with the Monitors. After the Trainer has time to review their form and address any concerns, the forms will be kept in the personnel files held at Autism NZ.
6. After the initial review (i.e., the Trainer's first 2 groups) by the Monitors, the responsibility for monitoring the Trainers will be divided so each Monitor is reviewing only half of the Trainers.
7. Should any additional monitoring requirements be requested from the National Autistic Society, Autism New Zealand, or the efficacy research team, Trainers will be notified immediately.

TRAINER SUPPORT AND DEVELOPMENT:

1. Trainers will have contact details for the Monitors and regular (at least one per programme) opportunities via email, telephone conversation and/or meeting to discuss any delivery concerns or questions that arise while delivering the Programme.
2. Trainers will meet together with all the other trainers for at least one day per year for professional development, networking, and to review requirements.

PROCEDURE FOR ADDRESSING PROBLEMS:

1. In the event a concern about Programme delivery accuracy or consistency arise, a letter outlining the specific concerns will be sent to the Trainer/s and a conference time arranged (personally, by email, or by tele-conference) to review the comments from the monitoring forms.

2. If required Trainers will have the opportunity to receive 'video feedback' from a Monitor to encourage Trainer self evaluation. During the feedback session, Trainers will be encouraged to review the Programme goals for the session or visit before reviewing their own footage. Following self-evaluation the Trainer and Monitor will 'brainstorm' ideas on how to avoid or improve the future delivery of the Programme. The Trainer and Monitor will then develop an ongoing monitoring plan to support the implementation of the new ideas.

3. After completing that group the Trainer will be further supported by ongoing monitoring by both Monitors for their next group [as outlined in (a) 1-5 above].

4. In the event the issue is not resolved the National Autistic Society and Autism New Zealand will be notified. Please note the National Autistic Society and Autism New Zealand reserve the right to revoke the Licence of registered Trainers of the NAS EarlyBird Programme.

Cumulative Data Sheet on Monitoring of NZ EarlyBird Trainers for Auckland Research Team.

Trainer	Session presentation from session video (comments and feedback from session evaluations)	Home Visit presentation from video (comments and feedback from evaluations)	Post Programme comments and feedback from questionnaires	Action taken by Monitors (if required)
T1	Positive group rapport, kept to programme well. “Positive and helpful”; “Very informative and helpful suggestions”	Positive rapport and evidence of coaching and EB strategies used by parents (eg. Visual cues for song, parents using less prompting, reduced language and more waiting by HVC).	“Loved them, easy in the home, very open, positive feedback from video experience”; “Very knowledge, awesome, inspiring, excellent. Put me at ease, informative recounting personal experiences with children.”	Reminder note sent outlining need for confidentiality so only early intervention professionals that the families have invited are to come to training session only in a support role (especially for home visits). Asked to review end of course parent reports for next programme (need to be focused more on what EB strategies they used rather than generic personal details about the children and families)
T2	Positive comments about ‘real life examples’ and use of videos. One participant had childcare concerns and another ESL participant found it difficult. “The teaching team is excellent”	Good rapport evident in evaluations, the trainer was ‘very reassuring’ and helpful. Evidence of coaching in evaluation forms and trainers notes (though not on tape)	“Ideas for everyday life”; “”Full of practical hints and tips”; “Ideas for dealing with behaviour problems”.	(As above) also a reminder for this trainer to send video footage of delivering the group sessions. Need to see session video tape.
T3	This trainer co-presented with a monitor for the 2nd EB programme. Excellent adherence to programme and good rapport with families.	Positive rapport with families and coaching evident on video and in notes.	This trainer moved out of NZ so post programme follow ups done by monitor.	Coaching from a monitor after 1st session to review issues of noise while taping, and the role of the EB trainer during home visits (eg letting parent work with child, facilitators not ‘experts’). Excellent with 2nd group. No further requirements

Cumulative Data Sheet on Monitoring of NZ EarlyBird Trainers for Auckland Research Team. (continued)

Trainer	**Session presentation from session video (comments and feedback from session evaluations)**	**Home Visit presentation from video (comments and feedback from evaluations)**	**Post Programme comments and feedback from questionnaires**	**Action taken by Monitors (if required)**
T4	Positive comments on sessions and use of videos ‘liked real life examples’.	Evidence of coaching in the evaluations. “Trainers personal experience with autism is very useful”	“Ideas for everyday life”; “”Full of practical hints and tips”; “Ideas for dealing with behaviour problems”.	Requested copies of trainers home visit notes to be sent in future. Need to see session video tape.
T5	Positive and good adherence to programme. “Excellent presenters”; “Excellent balance of presentation and interaction”; “Good pace – change of activities.”	Evidence of good rapport, coaching, personalising, and adherence to goals through tapes, trainers notes, and evaluations. “Good to spend time with instructors”; “Good to be reinforced by instructors”; “Instructors empowering”; “Excellent”.	Positive comments from questionnaires. “Empathetic and understanding”; “Great source of knowledge”; “First hand experience was very valuable”.	Requested tape of presenting a session.
T6	Positive comments from evaluations and evidence from session video that the presentation was clear, good rapport with group, well organised, good timing and adhered to programme. “The teaching team is excellent”	Positive rapport and evidence of coaching. Evidence of families using EB strategies on videos. “Easy in the home”; “Put me at ease”; “Useful ideas about getting eye contact”	Extremely positive feedback. “Loved them”; “Very open”; “experienced”, “Good level of formal/informal”; “Very knowledgeable and inspiring”; “Awesome”; “Approachable”; “Helpful and encouraging”; “Informative-recounting real experiences with children”.	Needed to remind trainer that the reports are to outline what the parents have learned and achieved (not to share personal information in reports). Reports in second group were excellent. No further requirements.

Cumulative Data Sheet on Monitoring of NZ EarlyBird Trainers for Auckland Research Team. (continued)

Trainer	**Session presentation from session video (comments and feedback from session evaluations)**	**Home Visit presentation from video (comments and feedback from evaluations)**	**Post Programme comments and feedback from questionnaires**	**Action taken by Monitors (if required)**
T7	One participant concerned about reading from book. Positive evaluation and feedback. “Excellent presenter”; “Pace and change of activities good”; Trainer came over and talked through step by step in smaller groups”; “Excellent balance of interaction and presentation”.	Evidence of adhering to goals on video tapes, good rapport, personalising and coaching. “Good to spend time with instructors”; “Discussion with trainer while viewing the video empowering”; Trainer helpful in helping us to make a change”; “Excellent gaining information from trainer”.	Positive comments from questionnaires. “Empathetic and understanding”; “Great source of knowledge”; “First hand experience was very valuable”.	Requested a tape of presenting a session.
T8	Co-presented with a monitor. Positive evaluations, observed clarity, rapport, timing, organisation, and adherence to programme as good.	Observed home visits as positive with good rapport, coaching and strategies, adhered to goals.	Positive comments after programme.	No further requirements.
T9	Co-presented with a monitor. Demonstrated clarity, good timing, well organised, adhered to programme and good rapport with families.	Observed home visits as positive with good rapport, coaching and strategies, adhered to goals.	Positive comments after programme. “We have a toolkit for managing everyday life now”	No further requirements.
T10	Videos reflected effective organisation and implementation of programme, clarity, timing, and rapport.	Evidence of coaching and adhering to goals in video tapes and trainer’s notes. Good rapport with families.	Positive comments, trainer’s experiences and use of real life examples. “It has been brilliant. We have and will continue to learn how to work –.hold great hopes for the future”.	Reminder to make 1 master copy of the video clips for ANZ rather than individual family tapes. No further requirements.

Appendix 4:

Language Analysis

How to Count Morphemes:

Firstly exclude all words read directly from the picture book in the toy set (see below for a transcript)

Count

1. The –s plural marker (e.g. cat/s, apple/s). Count it even when used on irregular plurals (e.g. mouse/s). Exception: plurals never occurring in the singular (e.g. pants, shoes, clothes) count as just one morpheme.
2. The –ed past tense marker (walk/ed, count/ed). The –ed morpheme is counted even when used improperly (go/ed, drink/ed).
3. The –ing progressive tense marker (walk/ing, count/ing).
4. The –s third person present tense marker (e.g. He like/s candy. Sue walk/s faster than Sara.) Exception: "does" counts as one morpheme.
5. Possessive –'s marker (e.g. mom's, boy's)
6. Contractions (e.g. she's, he'll, they're, what's, she'd, we've, can't, aren't). Exceptions: "let's," "don't", and "won't" are assumed to be understood as single units, rather than as a contraction of two words, so are just counted as one morpheme.

Do not count

1. Words which are false starts, reformulations, or repetitions unless the repetition is for emphasis. (e.g. "[then] then [he go] he went to the zoo" is counted as 6 morphemes; "No! No! No!" is counted as 3)
2. Compound words, reduplications, and proper names count as single words. (e.g. railroad, choo-choo, Big Bird)
3. Irregular past tense verbs and irregular plurals count as one morpheme. (e.g. took, went, geese, men)
4. Diminutives (e.g. doggie, horsie, dollie) and catenatives (e.g. gonna, wanna, hafta) count as one morpheme. It is assumed that the child understands these catenatives as single units, as opposed to understanding they are short for "going to," "want to," "have to," etc.
5. Do not count fillers (e.g., um, well, oh).

EXAMPLE:

#	**Child’s utterance**	**# of morphemes**	**Notes**
1	I want ball.	3	
2	That blue.	2	
3	Give it to me.	4	
4	Doggie’s hungry.	3	Doggie = 1 morpheme ‘s (is) = 1 morpheme
5	Doggie eated .	3	eated = 2 morphemes
6	xx wagon.	-	utterance excluded because of unintelligible word
7	I hafta go potty.	4	hafta = 1 morpheme
8	She likes toys.	5	likes = 2 morphemes toys = 2 morphemes
9	(He go) he go bye-bye.	3	bye-bye = 1 morpheme “he go” is repeated, only counted once
10	The mice are sleeping.	5	mice = 1 morpheme sleeping = 2 morphemes

Appendix 5:

Questionnaire Package

Administration of EarlyBird APQ

Instructions for personnel administering the EarlyBird APQ

Duration and administration setting: The APQ takes approximately 10 minutes to complete, but there is no time limit for completion. Respondents should be advised to set aside about 10 minutes to sit down in a quiet place, and to answer the items thoughtfully. The testing environment, which could be the respondent's home, should be well lit, and have a flat surface on which the respondent can write. The questionnaire can be answered using either a pen or a dark pencil.

Time of administrations

The pre-programme questionnaire (green) should be completed before participants begin the programme. Please hand out this questionnaire at the pre-programme visit, and either allow the parents to fill it in then, or ask that parents bring the completed questionnaire to the first session.

The post-programme questionnaire (yellow) should be completed directly after completion of the programme. Please hand this one out at the end of the last session, and either allow parents to fill it in then, or ask that they have it ready for you to collect at the post-programme visit.

The follow-up questionnaire (blue) should be completed six months after completion of the programme. Please take this one to the follow-up visit and ask parents to fill it in then.

At each point in time parents should have the option of either handing the questionnaire to you or sending it directly to the programme provider or researcher by mail.

Instructions for Administration: Ask the respondent to read through the instructions on the first page of the questionnaire. The following script is an example of instruction that could be given when administrating the APQ.

> *"The purpose of this questionnaire is to enable us to monitor on an ongoing basis the effectiveness of this programme. It is not a test of your performance as a parent. This questionnaire will take approximately 10 minutes to complete. Read the items carefully and rate how true the statements are for you on a 6-point scale, where '1' represents 'Not true at all' and '6' represents 'Definitely true'. Follow the example shown in the instructions and fill in the response bubble completely. Fill only one response bubble per item, and put an X over the response if it needs to be changed. There is no correct and incorrect answer. Remember to also answer the short questions on the last page of the questionnaire."*

EarlyBird Parent Questionnaire Form

Pre-Programme **Child-code:**

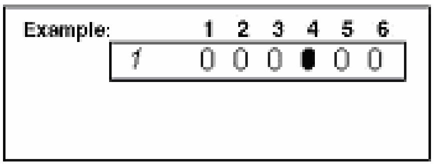
NOTE: This questionnaire takes approximately 10 minutes.
Please set aside 10 minutes to sit down in a quiet place to answer it thoughtfully.

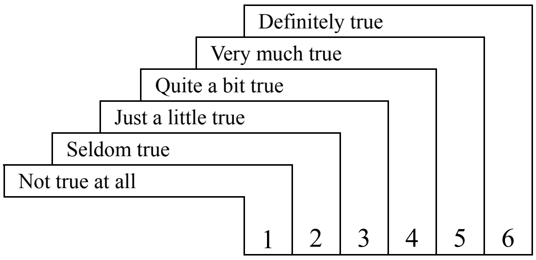
Parenting a child with autism is a challenging job. We are interested in personal experiences, views or beliefs around parenting your child with autism.

Please rate each item according to how TRUE the following statements are for you by using the following scale:

1 = Not true at all
2 = Seldom true
3 = Just a little true
4 = Quite a bit true
5 = Very much true
6 = Definitely true

For each question, fill in *__one__* bubble completely with black/blue pen or pencil. If you change your mind, put a X through that response, and fill in the *__one__* bubble you want to be counted.





		1	2	3	4	5	6	
1	I understand ways in which my child experiences the world differently from children without autism.	0	0	0	0	0	0	
2	I understand how autism influences my child's learning.	0	0	0	0	0	0	
3	I have a good understanding of why my child communicates the way he/she does.	0	0	0	0	0	0	
4	I can reflect on how I communicate with my child and change this accordingly.	0	0	0	0	0	0	
5	I warn my child before introducing something new.	0	0	0	0	0	0	
6	I match my language to a level my child understands.	0	0	0	0	0	0	
7	I wait until my child responds before I say something else.	0	0	0	0	0	0	
8	When I talk to my child I give him/her one instruction at a time.	0	0	0	0	0	0	
9	I use my facial expression and body language to encourage my child to take turns.	0	0	0	0	0	0	

Please return completed questionnaire in the freepost envelope provided to:
Dr Angelika Anderson
Research Centre for Interventions in Teaching and Learning, School of Education,
The University of Auckland, Private Bag 92019 Auckland, New Zealand

I am happy for my questionnaires to be used for research purposes: **Yes** ☐
No ☐

EarlyBird Parent Questionnaire Form

Not true at all	1
Seldom true	2
Just a little true	3
Quite a bit true	4
Very much true	5
Definitely true	6

	1	2	3	4	5	6
10 I know some games that I can play with my child that will teach him.	0	0	0	0	0	0
11 There are some games my child enjoys playing with me.	0	0	0	0	0	0
12 I have a good understanding of why my child misbehaves.	0	0	0	0	0	0
13 I use structure and visual cues to prevent or minimise problem behaviour.	0	0	0	0	0	0
14 I structure daily activities to minimise problem behaviour.	0	0	0	0	0	0
15 When my child has a tantrum I have a number of effective strategies.	0	0	0	0	0	0
16 I am able to change my child’s behaviour by the way I react to it.	0	0	0	0	0	0
17 Looking at the triggers and results of my child’s behaviour is helpful in managing him/her.	0	0	0	0	0	0
18 My child with autism dominates my life.	0	0	0	0	0	0
19…I feel trapped by the long-term responsibility of having a child with autism.	0	0	0	0	0	0
20…I feel confident that things will improve as I learn more about how to deal with my child.	0	0	0	0	0	0
21 I desperately need more help with parenting my child with autism.	0	0	0	0	0	0
22…I believe that I have some control over the future outcomes for my child.	0	0	0	0	0	0
23…I feel I can improve my child’s condition and future prospects.	0	0	0	0	0	0
24 My family functions well as a unit.	0	0	0	0	0	0
25 My child with autism dominates family life	0	0	0	0	0	0
26…The needs of other family members are met most of the time.	0	0	0	0	0	0
27 The people involved in my child’s care are in agreement on how to help or manage him/her.	0	0	0	0	0	0

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EarlyBird Parent Questionnaire Form

Now we'd like to ask for the following information about your ***CHILD***:
(Please tick the appropriate boxes if required)

Gender: ☐ Male ☐ Female

Ethnicity: ____________________

Age: ____________________

Diagnosis: ☐ Aspergers ☐ Autism ☐ Other – Please specify ____________________

Approximate age of diagnosis: __________

Your relationship to the child with autism:

☐ Father ☐ Mother ☐ Other – Please specify ____________________

If you have received any assistance in parenting the child with autism, specify.

Type of assistance	Approximate hours per week

Thank you for your assistance

Please return completed questionnaire in the freepost envelope provided to: Dr Angelika Anderson
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EarlyBird Parent Questionnaire Form

SCORING SHEET

Scale	ITEM	Score	
Knowledge	1 – 4	_____	
Communication	5 – 8	_____	
Play	9 – 11	_____	
Behaviour Management	12 – 15	_____	
Stress	16 – 19	28 – _____	⇨ **S** ® _____
Confidence	20 – 22	_____	
Family Functioning	23 – 25	_____	
Total Score	1 – 25	_____	

EarlyBird Parent Questionnaire Form

Post-Programme **Child-code:** ☐

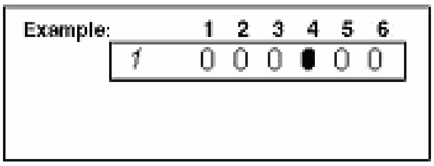
NOTE: This questionnaire takes approximately 10 minutes.
Please set aside 10 minutes to sit down in a quiet place to answer it thoughtfully.

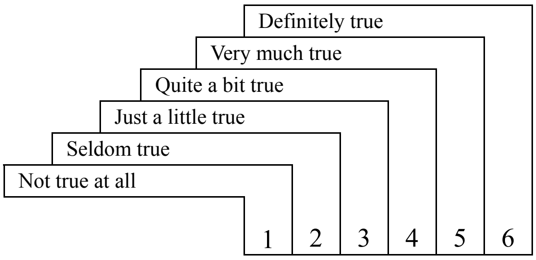
Parenting a child with autism is a challenging job. We are interested in personal experiences, views or beliefs around parenting your child with autism.

Please rate each item according to how TRUE the following statements are for you by using the following scale:

1 = Not true at all	3 = Just a little true	5 = Very much true
2 = Seldom true	4 = Quite a bit true	6 = Definitely true

For each question, fill in *one* bubble completely with black/blue pen or pencil. If you change your mind, put a X through that response, and fill in the *one* bubble you want to be counted.





		1	2	3	4	5	6
1	I understand ways in which my child experiences the world differently from children without autism.	0	0	0	0	0	0
2	I understand how autism influences my child's learning.	0	0	0	0	0	0
3	I have a good understanding of why my child communicates the way he/she does.	0	0	0	0	0	0
4	I can reflect on how I communicate with my child and change this accordingly.	0	0	0	0	0	0
5	I warn my child before introducing something new.	0	0	0	0	0	0
6	I match my language to a level my child understands.	0	0	0	0	0	0
7	I wait until my child responds before I say something else.	0	0	0	0	0	0
8	When I talk to my child I give him/her one instruction at a time.	0	0	0	0	0	0
9	I use my facial expression and body language to encourage my child to take turns.	0	0	0	0	0	0

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EarlyBird Parent Questionnaire Form

Definitely true
Very much true
Quite a bit true
Just a little true
Seldom true
Not true at all
1 2 3 4 5 6

	1	2	3	4	5	6
10 I know some games that I can play with my child that will teach him.	0	0	0	0	0	0
11 There are some games my child enjoys playing with me.	0	0	0	0	0	0
12 I have a good understanding of why my child misbehaves.	0	0	0	0	0	0
13 I use structure and visual cues to prevent or minimise problem behaviour.	0	0	0	0	0	0
14 I structure daily activities to minimise problem behaviour.	0	0	0	0	0	0
15 When my child has a tantrum I have a number of effective strategies.	0	0	0	0	0	0
16 I am able to change my child's behaviour by the way I react to it.	0	0	0	0	0	0
17 Looking at the triggers and results of my child's behaviour is helpful in managing him/her.	0	0	0	0	0	0
18 My child with autism dominates my life.	0	0	0	0	0	0
19…I feel trapped by the long-term responsibility of having a child with autism.	0	0	0	0	0	0
20…I feel confident that things will improve as I learn more about how to deal with my child.	0	0	0	0	0	0
21 I desperately need more help with parenting my child with autism.	0	0	0	0	0	0
22…I believe that I have some control over the future outcomes for my child.	0	0	0	0	0	0
23…I feel I can improve my child's condition and future prospects.	0	0	0	0	0	0
24 My family functions well as a unit.	0	0	0	0	0	0
25 My child with autism dominates family life	0	0	0	0	0	0
26…The needs of other family members are met most of the time.	0	0	0	0	0	0
27 The people involved in my child's care are in agreement on how to help or manage him/her.	0	0	0	0	0	0

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EarlyBird Parent Questionnaire Form

Now we'd like to ask for the following information about your ***CHILD*** *:*
(Please tick the appropriate boxes if required)

Gender: ☐ Male ☐ Female

Ethnicity: ____________________

Age: ____________________

Diagnosis: ☐ Aspergers ☐ Autism ☐ Other – Please specify ____________________

Approximate age of diagnosis: __________

Your relationship to the child with autism:

☐ Father ☐ Mother ☐ Other – Please specify ____________________

If you have received any assistance in parenting the child with autism, specify.

Type of assistance	Approximate hours per week

Thank you for your assistance

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EarlyBird Parent Questionnaire Form

SCORING SHEET

Scale	**ITEM**	**Score**	
Knowledge	1 – 4	_____	
Communication	5 – 8	_____	
Play	9 – 11	_____	
Behaviour Management	12 – 15	_____	
Stress	16 – 19	28 – _____	⇨ **S** ® _____
Confidence	20 – 22	_____	
Family Functioning	23 – 25	_____	
Total Score	1 – 25	_____	

EarlyBird Parent Questionnaire Form

Follow-up **Child-code:**

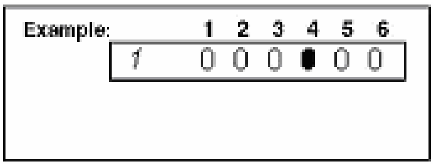
NOTE: This questionnaire takes approximately 10 minutes.
Please set aside 10 minutes to sit down in a quiet place to answer it thoughtfully.

Parenting a child with autism is a challenging job. We are interested in personal experiences, views or beliefs around parenting your child with autism.

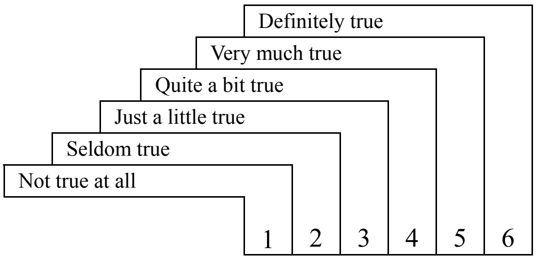
Please rate each item according to how TRUE the following statements are for you by using the following scale:

1 = Not true at all	3 = Just a little true	5 = Very much true
2 = Seldom true	4 = Quite a bit true	6 = Definitely true

For each question, fill in *one* bubble completely with black/blue pen or pencil. If you change your mind, put a X through that response, and fill in the *one* bubble you want to be counted.



Example: 1 2 3 4 5 6
1 0 0 0 ● 0 0



		1	2	3	4	5	6
1	I understand ways in which my child experiences the world differently from children without autism.	0	0	0	0	0	0
2	I understand how autism influences my child's learning.	0	0	0	0	0	0
3	I have a good understanding of why my child communicates the way he/she does.	0	0	0	0	0	0
4	I can reflect on how I communicate with my child and change this accordingly.	0	0	0	0	0	0
5	I warn my child before introducing something new.	0	0	0	0	0	0
6	I match my language to a level my child understands.	0	0	0	0	0	0
7	I wait until my child responds before I say something else.	0	0	0	0	0	0
8	When I talk to my child I give him/her one instruction at a time.	0	0	0	0	0	0
9	I use my facial expression and body language to encourage my child to take turns.	0	0	0	0	0	0

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EarlyBird Parent Questionnaire Form

Not true at all	1
Seldom true	2
Just a little true	3
Quite a bit true	4
Very much true	5
Definitely true	6

	1	2	3	4	5	6
10 I know some games that I can play with my child that will teach him.	0	0	0	0	0	0
11 There are some games my child enjoys playing with me.	0	0	0	0	0	0
12 I have a good understanding of why my child misbehaves.	0	0	0	0	0	0
13 I use structure and visual cues to prevent or minimise problem behaviour.	0	0	0	0	0	0
14 I structure daily activities to minimise problem behaviour.	0	0	0	0	0	0
15 When my child has a tantrum I have a number of effective strategies.	0	0	0	0	0	0
16 I am able to change my child’s behaviour by the way I react to it.	0	0	0	0	0	0
17 Looking at the triggers and results of my child’s behaviour is helpful in managing him/her.	0	0	0	0	0	0
18 My child with autism dominates my life.	0	0	0	0	0	0
19…I feel trapped by the long-term responsibility of having a child with autism.	0	0	0	0	0	0
20…I feel confident that things will improve as I learn more about how to deal with my child.	0	0	0	0	0	0
21 I desperately need more help with parenting my child with autism.	0	0	0	0	0	0
22…I believe that I have some control over the future outcomes for my child.	0	0	0	0	0	0
23…I feel I can improve my child’s condition and future prospects.	0	0	0	0	0	0
24 My family functions well as a unit.	0	0	0	0	0	0
25 My child with autism dominates family life	0	0	0	0	0	0
26…The needs of other family members are met most of the time.	0	0	0	0	0	0
27 The people involved in my child’s care are in agreement on how to help or manage him/her.	0	0	0	0	0	0

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EarlyBird Parent Questionnaire Form

*Now we'd like to ask for the following information about your **CHILD**:*
(Please tick the appropriate boxes if required)

Gender: ☐ Male ☐ Female

Ethnicity: ____________________________

Age: ____________________________

Diagnosis: ☐ Aspergers ☐ Autism ☐ Other – Please specify

____

Approximate age of diagnosis: ____________

Your relationship to the child with autism:

☐ Father ☐ Mother ☐ Other – Please specify

____

If you have received any assistance in parenting the child with autism, specify.

Type of assistance	Approximate hours per week

Thank you for your assistance

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EarlyBird Parent Questionnaire Form

SCORING SHEET

Scale	**ITEM**	**Score**	
Knowledge	1 – 4	_____	
Communication	5 – 8	_____	
Play	9 – 11	_____	
Behaviour Management	12 – 15	_____	
Stress	16 – 19	28 – _____	⇨ S ® _____
Confidence	20 – 22	_____	
Family Functioning	23 – 25	_____	
Total Score	1 – 25	_____	